

# A QUALITATIVE STUDY EXPLORING THE EXPERIENCES OF ACCESS AND PATHWAYS TO HEALTH CARE AMONG BME COMMUNITY GROUPS RESIDING IN AYRSHIRE

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Professional Doctorate in Health Psychology

Queen Margaret University, Edinburgh

The main objective of the present study was to gain insights into the perspectives of BME community groups' experiences of accessing general and sexual health care services in Ayrshire. Semi-structured interviews were conducted with 11 participants, n = 5 men (age range: 32-65; mean age = 52.4 years), and n = 6 women (age range: 27-60; mean age = 47.67 years). Data were analysed employing Interpretative Phenomenological Analysis (IPA). The analysis is illustrated through the use of four super-ordinate themes: 'It's a Trust Thing', 'Minding the Gap(s)', 'Sexual Health: a Culture of Silence', and 'Personal Perception of Risk'. The implications for clinical practice, health promotion, health service development, and the direction of future research will be discussed.

**Elizabeth  
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A qualitative study exploring the experiences of access and pathways to health care among community groups residing in Ayrshire



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EDINBURGH

*“...we don’t understand the system in this country, how it is monitored, who to approach, what to do...so, who do you approach? What do you say? When do you approach? In what circumstances?”*

*Joseph (Indian Sikh)*

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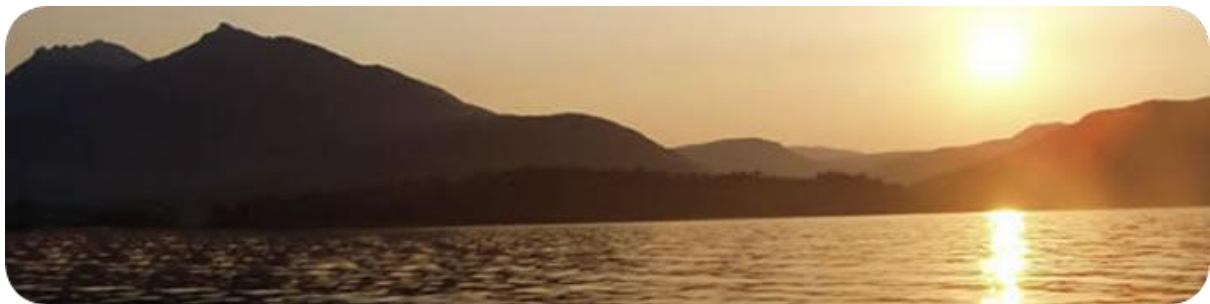
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## Abbreviations

BME	Black and Minority Ethnic Groups/Communities/Populations
IPA	Interpretative Phenomenological Analysis
HIV	Human Immunodeficiency Virus
LEP	Lack of English Proficiency
BSE	Breast Self-Examination
RSC	Regular Source of Care
CBT/FA	Cognitive Behavioural Functional Analysis
LTHC	Long-term conditions
PCC	Person-Centred care
HBC	Health Behaviour Change
CVD	Cardiovascular Disease
SES	Socio-Economic Status
QOL	Quality of Life



Isle of Arran, North Ayrshire

## Abstract

A review of the literature showed that Black and minority ethnic (BME) communities carry a disproportionately higher burden of illness than the general population and experience greater inequalities in health and health care provision. A growing body of research confirms that BME groups are under-represented in research. The main objective of the present study was to gain insights into the perspectives of BME community groups' experiences of accessing general and sexual health care services in Ayrshire. Semi-structured interviews were conducted with 11 participants, n = 5 men (age range: 32-65; mean age = 52.4 years), and n = 6 women (age range: 27-60; mean age = 47.67 years). Data were analysed employing Interpretative Phenomenological Analysis (IPA). The analysis is illustrated through the use of four super-ordinate themes: 'It's a Trust Thing', 'Minding the Gap(s)', 'Sexual Health: a Culture of Silence', and 'Personal Perception of Risk'. The findings both support and add to the existing trust literature by presenting a heuristic model of trust, and by showing that participants trust is dynamic in character, has a role, and serves various roles and functions that impact decisions about accessing health services. Significant gaps in knowledge about available health services and unique communication challenges that prevent full access to health care and health promotion information were found, resulting in unmet needs. Analysis charted culturally driven factors that prohibit discussions about sexual health concerns and found complex cognitions involved in the personal perception of risk that was meaningfully understood by participants that direct towards understanding risk in terms of a heuristic model. The implications for clinical practice, health promotion, health service development, and the direction of future research will be discussed.

## Preface

The direction for the current study was informed by findings of a scoping project (Chapter 1. Sections: 1.1; 1.3.1.3), which was commissioned by the Public Health Department, NHS Ayrshire and Arran (April-June, 2009). This piece of work was conducted in response to a call for research from the former Scottish Executive to focus solely on identifying the wider determinants of health of the Black and Minority Ethnic (BME) population in Scotland. The main aim of the scoping project was to build a preliminary data set of the characteristics of the BME community groups across Ayrshire and to gain an understanding of the low uptake of general and sexual health care services across the county. The results from this line of enquiry were somewhat limited due to methodological issues, and a reluctance of individuals from various BME community groups to take part in the project.

The present study benefited from the scoping project, due to having already established trust and rapport with key community members (Chapter 2: Section: 2.4.2), who were instrumental in arranging interpreters (Chapter 2: Section: 2.9.1) and informing respective community groups about the study. The findings from the scoping project were used to direct the development and approaches used in the present study (Chapter 2). The present study aimed to gain sights into the perspectives of BME community groups' experiences of accessing health care services in Ayrshire (Chapter 1: Section: 1.7.1).

This thesis synthesises a wide range of studies drawn from health psychology, neuropsychology, public health, and the wider health literature (Chapter 1). Chapter 2 details the most salient features of the design, and the methodological approach employed by the present study. The results are presented in four chapters (Chapter 3 through to Chapter 6), which offers an exhaustive analysis of participants' accounts. Chapter 7 provides a general discussion of the results, charting the most salient findings. In Chapter 8, a

conclusion of the findings is presented, along with a critical evaluation of the methods used.

A series of recommendations are put forward as a synopsis of key findings, which have implications for the direction for future research, clinical practice, health promotion, and health service development. The appendix section follows on from Chapter 8, which comprises of tables, charts, and other relevant documentation (e.g. participants' information sheet & consent form). A cross-referencing system has been used throughout this thesis to prevent replication of salient points and to help navigate the reader to applicable tables, charts, and relevant Chapters and section(s).

# Chapter 1

## 1 Introduction

Access to health care is important for increasing the best possible outcomes for overall physical, sexual and mental health, and for improving patients' quality of life (Institute of Medicine, 2014; WHO, 2015). Access to health care is also central to the sustainability of the health care system, for continued service development, and for the improvement in health policy (Levesque, Harris, & Russell, 2013). While the term access is used to describe factors influencing the use of health care services, opinions differ as to whether the emphasis should focus on describing characteristics of the health care system (e.g. resources, financial affordability), the service user, or to the extent to which societal factors exert an effect on access (Harris, Harris, & Roland, 2004; Adler & Newman, 2002; Levesque, Harris, & Russell, 2013). Here, access is defined as the opportunity to obtain timely and appropriate health care in situations of perceived need for care (Levesque, Harris, & Russell, 2013). Access is understood as resulting from the interface between characteristics of the individual, organisational and environmental factors, health behaviours, and health status (Penchansky & Thomas, 1981). The practical consequence of defining and measuring access can be considered as a series of conceptual, methodological, and theoretical issues to be resolved to establish the extent to which access is equitable (Millman, 1993). Equitable access to health care is also associated with timeliness, as typified by definitions such as "*the timely use of personal health services to achieve the best health outcomes*" (Fiscela, Franks, Gold, & Clancy, 2000). Szczepura (2005) argues that definitions of access that only take account of "receipt of care" are inadequate without accounting for the process of accessing care, and the quality of care received. This point is particularly salient to the present review of access, as there is a growing body of studies discussing ethnic variations in access to, and utilisation of health care and disparities in the quality of care received

(Atkinson et al., 2001; McLean, Campbell, & Cornish, 2003; Nazroo, 2003a; Bhopal, 2007; Goddard, 2008; Williams & Wyatt, 2015; Hulme et al., 2016). The focus of this review is to explore the impact of multi-level factors on access, to identify pathways and process which may prevent some BME community groups from receiving timely and appropriate health care in situations of perceived need for care (Levesque, Harris, & Russell, 2013).

## 1.1 Background

Consistent evidence across health care systems show that some Black and minority ethnic (BME) groups experience greater disparities in health (Nazroo, Jackson, Karlsen, & Torres, 2007), with studies showing inequity in health care access, and treatment provided by the NHS (Szczepura, 2004; Bharj & Salway, 2008). A growing body of literature shows that certain BME groups have poorer health than the general population, although some fare much worse than others, and patterns vary for different health conditions (Chapter 1: Section: 1.2.1.2-1.2.1.3). Dixon-Woods et al. (2005) argue that some ethnic groups have historically been disadvantaged in obtaining full and equal access to health care. Various writers have argued that there are organisational and structural barriers to health; however, more idiographic accounts are needed to document the lived experiences of individuals of the various BME communities throughout Scotland, in an attempt to assess the level of need, and develop an appropriately responsive and culturally sensitive health care service.

The scoping project, which underpinned the present study, was successful in terms of offering a level of insight into the experiences of accessing local health services in Ayrshire. This project was limited in terms of a range of methodological issues, such as; the lack of depth and breadth of the data captured, a small sample size, lack of female participants, and the limited range of individual's from a wider range of BME community groups. The present study benefited from the scoping project, due to having already established trust and rapport with key community members, who were instrumental in arranging interpreters (Chapter 2:

Section: 2.9.1) and informing respective community groups about the study. The findings were used to direct the development and methods used in the present study (Chapter 2).

## **1.2 Andersen's Socio-Behavioural Model of Health Care Utilisation**

The Andersen's Socio-Behavioural Model of Health Care Utilisation (from here on will be referred to as the Andersen model) (Andersen & Newman, 1973; Andersen, 1995), has been widely used for explaining patterns of health care use by the general population (Murimi & Harpel, 2010; Berglas, Hucles, Constantine, Jerman, & Rohrbach, 2016); to offer measures of access (Austin, Andersen, & Gelberg, 2008; Elhai, Grubaugh, Richardson, Egede, & Creamer, 2008; Forbes et al., 2008); to identify organisational and professional factors affecting access (Dutton, 1986; Brenes-Camacho & Bixby, 2009); to predict health care use in a range of patients groups living with long-term health conditions (Nogueira, Ribeiro, & Cruz, 2009; Lee et al., 2015; Lo, Parkinson, Cunich, & Byles, 2016), and to understand ethnic equity in access to health care services (Ariza-Montoya, & Hernandez-Alvarez, 2008). The Andersen model proposes that access to, and use of health care services is a function of four key domains: 1. structural factors (community and environment; health system level); 2. Population and individual characteristics (predisposing, enabling, and need-related factors); 3. Health behaviours (personal health practices, access, and use of health services); and 4. Health outcomes. The model includes feedback loops, which are interrelated and dynamic.

### **1.2.1 Structural Factors: Community and Environment**

#### **1.2.1.1 Ayrshire's Population Diversity**

According to Scotland's census 2011, there has been an unprecedented demographic change across Ayrshire, with the Black African community growing exponentially over the past decade (Census 2001; Census, 2011). The Black African community is now the largest BME community in Ayrshire (2,691), with the majority of the community members residing in East Ayrshire (Appendix: 1). The next largest BME group is the Pakistani community (2,140),



followed by the Mixed Ethnicity community group (2,115), Indian (2,023), Chinese (1,865), 'Asian Other' (1,185), and the Caribbean community (718). Other ethnic groups represented across Ayrshire include people from the European Union member States, the Middle East, North and South American, and New Zealand.

Scotland's Census (2011) supports other documented evidence showing that the demographic profile is changing throughout the UK. Notwithstanding the inclusion of data sets that have not been present in historical census reports (e.g. general health and long-term health problems, or disabilities), there has been a missed opportunity to document the proportion of BME community members who have general health problems, or live with a long-term health condition (LTHC), or disability; despite ethnicity being routinely captured in health care settings in Scotland from 2008. In addition, despite the 2011 census defining ethnicity more clearly and comprehensively than previous Census data, there are concerns about aspects of the data that make it difficult to interpret or to allow comparisons to be made against current and previous census data. For example, there were several entries to account for various community groups and sub-groups across each council district (e.g. Caribbean or Black; Caribbean or Black; Caribbean-Scottish or Caribbean British; Caribbean or Black or Black Scottish or Black British), presented in the same section, and two entries for Asian, Asian Scottish or Asian British with differential statistics.

#### **1.2.1.2 Incidence and Prevalence of Long-Term Health Conditions across BME Groups**

The 1999 UK health survey reported the prevalence of diabetes is greater in Bangladeshi communities (10.6%), closely followed by Pakistani (8.7%), and Indian communities (7.7%). For the Bangladeshi and Pakistani population, this represented an almost five times higher prevalence than the general population. The prevalence in black Caribbean men was similar to Indians. In the UK, early deaths from coronary heart disease (CHD) in Indian, Bangladeshi, Pakistani, and Sri Lankan communities were reported to be about 50% higher

than the national average. More recent data show that South Asian communities continue to experience greater cardiovascular morbidity and mortality rates (British Heart Foundation, 2015a, 2015b), greater risk of developing respiratory diseases (Bhopal et al., 2015; Simpson et al., 2015), and continue to have a higher burden of pre-diabetes and diabetes, compared to the wider population (Deepa, et al., 2015).

A National Statistics Publication for Scotland (2015) reports that in 2014, 16% of all adults residing in Scotland were living with a diagnosis of Cardiovascular Disease (CVD), and 6% of adults were living with diabetes (men: 8%, women: 5%). There was a 4% increase in the prevalence of asthma (adults: 17% for adults, an increase from 13% in 2003). The data for Chronic Obstructive Pulmonary Disease (COPD) remained unchanged since 2008. The prevalence of obesity has increased by 10 points (28% obese), and 5% of all adults are overweight. Health-compromising behaviours, such as alcohol consumption has reduced (men from 53% to 46%; women from 42% to 36%). Yet, the prevalence of smoking remains high. The use of e-cigarettes is higher among current (15%) and ex-smokers (7%), compared to people who have never smoked cigarettes regularly (1%). Adults consumed less than the recommended 5 daily fruit and vegetables (average consumptions: 3.1 portions of fruit and vegetables), and 37% did not follow the recommended level of activity per week (150 minutes of moderate, or 75 minutes of vigorous activity per week).

### **1.2.1.3 The Health Status of Scotland's BME Groups**

The health status of Scotland's BME communities varies widely, with the majority of BME groups reporting better health than the White Scottish ethnic group (Scottish Government, 2015). Older men across the majority of ethnic groups reported better health than older women. Older Indian, Pakistani and Bangladeshi women, reported "poor health", and rated their health as being significantly poorer health than older men in these ethnic groups. Women from all the other ethnic groups reported lower rates of 'health problem or disability'

than individuals from the White Scottish ethnic group. Chinese, White Polish, and 'Other Asian' group reported the lowest rates of 'health problem or disability'. Gypsy/Travellers in Scotland experience the poorest health, with participants reporting twice the White Scottish rate of 'health problems or disability', and over three and a half times the white Scottish rate of poor general health. White Polish people under 65 reported relatively good health, whereas those aged 65 or over reported relatively poor health. Chinese older age seems to be strongly associated with an increase in poorer reported health. This data set echoes findings across ethnic groups in England and Wales, allowing for comparison across the three nations (ESRC, 2013). Data were analysed using indirect standardisation methods, which calculates how much higher or lower the group's rate of disability or poor health is compared to the average for Scotland (e.g. calculation applies the Scotland age-specific rates to the groups' population). The authors suggest that caution needs to be used when interpreting these results, as ethnic groups tend to have younger age profiles than the general population. Further, the reliability of surveys using closed-ended questions may have a lower validity rate, and data errors are common due to question non-response; thereby increasing the risk of response bias, which can have an impact on the validity of the study's findings (Nederhof, 1985; Furnham, 1986).

#### **1.2.1.4 Social Inequalities, Health and Access**

Evidence shows that immigrants are more vulnerable to social and economic disadvantage, which has the potential to negatively impact health, and access to health care (Arenas, Goldman, Pebley, & Teruel, 2015; Galanis et al., 2013; Busetta, Cetorelli, & Wison, 2017). The most vulnerable individuals from these groups are more likely to be excluded from a number of social and community aspects of life, such as participation in education and health care, and from 'social production and consumption' (Shaw, Dorling, & Smith, 2006). They are also at increased risk of experiencing a lack of, or inadequate language services (Shaw,

Dorling, & Smith, 2006), which can seriously impact access, and health outcomes (DeCamp, et al., 2015).

Previous research found that homeless people are at increased risk of alcohol and substance misuse, being a victim of violence (St Mungo's, 2009; Crisis, 2014), and are forty times less likely to be registered with a GP compared to the general population (Crisis, 2007). Bangladeshi households are 63%, and Black African households are 75% more likely than white British households to suffer "housing deprivation". White Gypsy and Irish Traveller households are seven-and-a-half times more likely to experiencing housing deprivation (Census, 2011). In addition, home ownership amongst all ethnic groups decreased between 1991 and 2011 and was lowest among Black African (24%), and Arab communities (27%), compared to Indian, Chinese and White UK citizens (50%).

Homelessness is disproportionally experienced by migrant groups (Chain, 2015), and higher levels of unemployment, poverty and lower socioeconomic status (SES) have been found among BME groups compared to the general population (Race Equality Foundation, 2013; The Runnymede Trust, 2014; Joseph Rowntree Foundation, 2016). Joseph Rowntree Foundation (2016), reports that in 2015, 5% of White 16-24-year-olds were unemployed, compared to 29% from the Black communities, 24% of Asian, and 23% of those from 'other ethnic backgrounds'. Throughout the UK, BME communities are less likely than white people to be paid the living wage. The BME group most likely to be paid the minimum wage include Bangladeshi males (57.2%), followed by 38.7% of Pakistani males, 37% of Pakistani women, and 36.5% of Bangladeshi women (Joseph Rowntree Foundation, 2016). Strong consistent evidence across the UK shows that Pakistani and Bangladeshi communities were the most likely to be in 'persistent poverty', followed by Black African and Black Caribbean communities (Race Equality Foundation, 2016).

The Economics Foundation (2012), reported that South Ayrshire was ranked along with the Welsh Valleys (Merthyr Tydfil and Blaenau Gwent), as being in the bottom three areas with the highest percentage of people scoring badly on at least one wellbeing measure. North Ayrshire was found to be one of the areas with the largest percentages scoring badly on at least one measure. The observed effects endured even after controlling factors known to affect wellbeing (e.g. relationship status, labour market status, and home ownership). Further analysis using UK wide geographic data showed that the areas with higher levels of deprivation had lower levels of well-being. The data set used in analysis contained 200 variables, which were analysed using multivariate linear regression. The authors report excluding subjective health questions in the analysis, due to concerns about response bias. Yet, health is associated with subjective well-being (Stephoe, Deaton, & Stone, 2015). Debatably, some of the association that are found with self-assessed health may be due, not to the genuine relationship between health and subjective well-being, but to the tendency to respond more positively to such questions in surveys than others (response bias) (Mindell, al., 2015).

#### **1.2.1.5 Structural Factors: Health System Level**

An equitable use of health care among cultural and linguistic minority populations is an important goal within health care systems (Agency for Healthcare Research Quality, 2007). Prior work has addressed models for understanding the equitable use of health care, and for implementing effective interventions to reduce the disparities in health care (Andersen, 1995; Cooper, Hill, & Powe, 2002). In terms of the provision of health care services, some authors argue that there is inequity in health care provision for the most deprived and vulnerable groups in society, while the most affluent and advantaged groups tend to receive the most health care (Cookson, Propper, Asaria, & Raine, 2016). Watt (2015), argued that more funding is made available within health practices for the most affluent of the population, compared to the most deprived populations, which impacts access and use of services for

the most vulnerable within society. There is also evidence supporting the possibility that disparities in access are due to socioeconomic differentials, and experiences of racial harassment and discrimination (Nazroo, 2003b). To illustrate, the literature indicates that people from BME communities who are living with chronic physical or mental health problems, and are at risk of poverty or social exclusion, are particularly disadvantaged when it comes to accessing services, and receiving equal quality of care (Atkinson et al., 2001; Bhopal, 2007; Goddard, 2008; McLean, Campbell, & Cornish, 2003; Nazroo, 2003a). However, more work is required to document the experiences of BME communities at higher risk of health disparities in Scotland and to understand more fully the relative role of structural factors, which serve to facilitate or act as barriers to access among Scotland's BME communities.

#### **1.2.1.6 Initiatives to Address Disparities in Health for BME Communities**

The Scottish Public Health Observatory (2015) stated that there is a policy commitment in Scotland to address inequalities in health and to tackle discrimination against BME groups. The Scottish Government (2015) announced their commitment to treating BME communities as equal members of the Scottish population, with an expressed desire to understand their health care needs. The Scottish Government promotes the notion of a culturally competent health care system that recognises diversity, individual needs, and cultural preferences when planning and delivering services (Scottish Government, 2003), and advocates the following definition of cultural sensitivity, and cultural competence:

*“...a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations, where culture refers to integrated patterns of human behaviour that include the language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious, or social groups, and competence implies having the capacity to function*

*effectively as an individual or an organisation within the context of the cultural beliefs, behaviours and needs presented by patients and their communities"*  
(Association of American Medical Colleges, 2010).

However, there remain concerns in Scotland about the "severe lack" of information on the health of Scotland's BME communities (Scottish Public Health Observatory, 2015), and about the lack of explicit strategies to address the mental health care needs of Scotland's BME community groups (The Mental Health Foundation, 2016). There are also concerns about policy and its consequences, particularly with regard to making generalisations about why some social groups experience greater health disparities (McIntyre, 2013). McCartney (2013), suggests this issue is maintained due to a trend of "drifting" from discussions about social determinants of health and wellbeing, and inequalities in society, to drawing conclusions about specific social groups, or particular interventions and/or health services; without due consideration of the relevance of the processes linking these complex issues. Alliance Scotland (2016) continues to work with the Scottish Government to resolve these issues while giving a voice to the people of Scotland living with LTHC, and their carers. However, more evaluation is required to determine the extent to which Alliance Scotland support culturally sensitive models of care, or engage with BME communities to support their efforts to access timely, and appropriate health care services.

A UK study found a range of challenges to health care professionals applying a culturally sensitive model of care (Kai, Beavan, & Faull, 2007). There was strong evidence in this study to support the notion that health care professionals experience problems with dissonance and incongruity in terms of applying a culturally sensitive approach in their work with ethnically diverse patient groups. This study showed that health care professionals from both primary and secondary care settings experience varying degrees of uncertainty and disempowerment during consultations. Health care professionals were concerned about

“*getting it wrong*”, and had specific concerns about patients’ perceptions that they were being either “disrespectful”, “*discriminatory*” or “*racist*”. These concerns were fuelled by a lack of cultural-specific knowledge (e.g. differential cultural beliefs, and attitudes), a lack of shared language, and stereotypical expectations of patients. Any one of these factors carries with it the potential to negatively impact the quality of care patients from BME communities receive while serving to perpetuate ethnic disparities in health (Lanceley & Cox, 2007; Manson, 1988; Centres for Disease Control and Prevention, 2011). These findings raise concerns about current training to support healthcare professionals in Scotland to be more able to respond appropriately to understand and to address the health care needs of patients from BME communities.

#### **1.2.1.7 Regular Source of Care**

Studies indicate that having a regular source of health care (RSC) increases the likelihood of receiving better-coordinated care, better treatment options for chronic and acute health conditions, fewer delays in care, and access to preventive care (NHS Scotland, 2015). Studies show that compared to white patient groups, BME populations are less likely to have an RSC, even when socioeconomic status (SES), and health conditions are controlled for (Atkinson, et al., 2001; Shi & Stevens, 2005). This may explain in part why some BME communities experience poorer health compared to the wider population (Sections: 1.2.1.2 - 1.2.1.3). Much has still to be learned about Scotland’s BME community groups experiences of access to primary, specialist, and preventative care services, which take account of their individual characteristics (e.g. beliefs, knowledge, emotions), and their “*personal world*” (Smith, 2011b).

#### **1.2.1.8 Person-Centred Care & Shared Decision Making Initiatives**

The Scottish Government’s 2020 vision for achieving sustainable high-quality healthcare services across Scotland focuses on the expansion of person-centred care (PCC) initiatives



as a device for the development of knowledge, skills, and power; with the objective of enabling individuals to become active participants in their own healthcare (Clissett, Porock, Harwood, & Gladman, 2013; Picker Institute, 2015). While PPC is increasingly recommended across health systems, there remain concerns about defining and operationalising the approach (Lawrence & Kinn, 2012; Jefferies, & Horsfall, 2013; Chewing et al., 2012; Scholl et al., 2014). The blurring of the meaning of PCC increases the likelihood of this concept being implemented in wide-ranging ways (Silva, 2014; Smith et al., 2011), which may explain, in part the reported variation of the impact of interventions implementing PCC approaches (Lewin et al., 2001; Dwamena et al., 2012).

Patients' participation in decision making is often considered to lie at the crux of PCC (Weston, 2001), and is associated with better health outcomes, and with greater satisfaction with the consultation process (Resnick & Hart, 2003; Resnick & Jensen, 2003; Medina-Mirapeix et al., 2013). Integrating best practice PPC approaches with shared decision making in clinical practice has the potential to 1. reduce unwarranted variations in practice; 2. improve patients' experience of access; and 3. support the sustainability of the healthcare system (Bolster & Manias, 2010; The Kings Fund, 2012). However, some authors argue that shared decision making is anything but centred on the patient as it creates tensions for some patients who do not wish to participate in decisions (Edwards & Elwyn, 2006). Others suggest that PCC could be more readily measured by patients' satisfaction with care, and by aligning patients' preferences with decision making to their actual decisional responsibility (Légaré et al., 2012a; 2012b). Edwards & Elwyn (2006) propose that healthcare professionals would do well to explicitly ask about, and respect a "*patient's preferences of role*", and to re-align their approach during the consultation so as to "*defer to the patient's preferences*".

### 1.2.1.9 Challenges to Supporting Self-Management

Supporting patients' efforts in self-management strategies is a key objective of the 2020 vision (NHS, 2016). Yet, training of health professionals in theoretical frameworks, and skills underpinning the facilitation of self-management is not widely available (Dures et al., 2014). There also remain concerns about clinicians who consider support for self-management lies out with their responsibility, or who report feeling the transferral of power in the relationship with patients difficult to manage (Chew-Graham, May, & Perry, 2002; Wileman, May, & Chew-Graham, 2002; Stone, 2014). Limited consultation time and workload pressures also present a challenge for clinicians to explore new ways of working (Royal College of General Practitioners, 2015).

A qualitative study exploring the consultation with patients with medically unexplained symptoms found that GPs were very aware of the suffering experienced by their patients, and understood how they felt "*marginalised and dismissed*" by the health system (Stone, 2014). Despite having a strong ethical commitment to care for patients, there was evidence to suggest physicians experienced negative feelings towards patients (frustration and helplessness), which were "*uncomfortable and confronting*". Some senior physicians were uncertain about their clinical role, particularly so in regard to where their professional responsibilities began and ended. These findings raise concerns about the availability of training to help physicians manage their feelings more effectively, and to develop ways of understanding and managing the therapeutic relationship, to help patients manage their medically unexplained symptoms (Stone, 2014).

A review of the literature investigating chronic illness suggests that supporting patients to self-manage can improve their quality of life (QOL), reduce clinical symptoms, facilitate access to health care resources, and reduce health service utilisation (Kennedy et al., 2007). A "Keep Well" health behaviour change (HBC) intervention (targeting adults at risk of

preventable chronic ill health), in areas of high deprivation in Scotland, found mixed results (Hooke, Wyper, & Tamvakos, 2011; NHS Lothian, 2012; Hair & Wyper, 2013; Clarke et al., 2010). The primary focus was the reduction of cardiovascular disease (CVD) risk (e.g. smoking cessation, weight loss, and statin therapy). An evaluation of the programme concluded that the mixed results were largely due to variations in the delivery of self-management approaches (Fife, MacMillian, Fleming, & Callaghan, 2011). There is, however, evidence to argue that some patients in Scotland may not be benefiting from advice, treatment, and referrals, and weaker evidence to suggest that some patients may feel less able to take control of their health in the absence of ongoing support (Fife, MacMillian, Fleming, & Callaghan, 2011). However, more work is needed to understand the health behaviours of Scotland's BME communities as a preliminary step to reducing inequalities in CVD mortality in high-risk groups; and to support HBC in BME communities vulnerable to social and economic disadvantage, which has the potential to negatively impact access to health care, and health outcomes (Cooper & Darling, 2012).

### **1.2.9.1 Challenges and Barriers to Access**

#### **1.2.9.1.1 Organisational Racism**

Studies exploring ethnicity and health argue that organisational racism affects access to health and health care in non-white minority communities, resulting in racial disparities in health status (Richardson, 2010). Organisational racism can impact upon BME groups' health directly through health-related policies, and through other factors indirectly (Health and Race Equality Forum, 2015; Sunderland Local Involvement Network, 2012). In this seminal paper, Nazroo (1998) argued that racism, ethnic identity and the relevance of "*group affiliation and culture*", contribute to BME communities experiencing a greater risk of mental health problems. Weerasinghe (2012), Holland, and Ousey (2011), suggest that organisational racism contributes to the problems experienced by the Black community through several recognized pathways: 1. reduced access to employment, housing, and education and/or increased exposure to risk factors (e.g., avoidable contact with police); 2.

adverse cognitive/emotional processes; 3. allostatic load and associated pathophysiological processes (e.g. increased inflammatory markers); 4. diminished uptake of health promoting behaviours (e.g., exercise, healthy eating, uptake screening programmes), and increased participation in health-compromising behaviours (e.g., alcohol consumption, smoking, drug misuse), either directly as coping resource, or indirectly, through reduced self-regulation; and 5. physical injury as a result of racially-motivated violence (Pries, Ferdinand, Perry, & Kelaher, 2014; Harrell, et al., 2011; Brondolo, Brady, Libby, & Pencille, 2011). There remains a need to explore the experiences of Scotland's BME communities to establish possible concerns about racism at the community or health care system level.

#### **1.2.9.1.2 Stigma and Discrimination in Health Care**

Research investigating the experience of stigma and discrimination in health care come mostly from the mental health and HIV literature. There are however great variations in the definitions, frameworks, and tools to measure stigma among different populations, and understanding of its prevalence and effects among people affected by HIV. One way through which stigma acts on an individual's sense of well-being is through increased vulnerability to discriminatory behaviour (Deacon, 2006). Most stigma frameworks differentiate between experiences of discriminatory behaviour (interpersonal discrimination) and internalised stigma (feelings of low self-worth & felt stigma) (Link & Phelan, 2001). Criticism has been levied against national programmes addressing stigma as rarely considering diverse cultural understandings of health, particularly from BME communities, who may have different explanatory frameworks and who experience discrimination and multiple forms of stigma, including racism and disempowerment (Harris et al., 2006; Nazroo, 2003b). Researchers suggest that community approaches to tackling stigma are more valuable than top-down public education approaches (Knifton et al., 2010; Quinn et al., 2014). Before this can be achieved, it is important to build a community sample data set throughout Scotland, to establish the key areas of concern of those most at risk of

A qualitative study exploring the experiences of access and pathways to health care among BME community groups residing in Ayrshire experiencing stigma and discrimination.

### **1.2.9.1.3 Patient Engagement**

Patient engagement refers to collaborative partnerships between patients and their families to improve health, and health care across various levels of the health system including individual health care, organisational design and governance, and policy making (Carman et al, 2013; Danis & Solomon, 2013; Chu & O'Brien, 2013). Key recommendations include a need for information about strategies for engaging patients and families who have difficulty navigating, and using the health care system, such as those with a lack of English proficiency (LEP), and limited health literacy (Carman et al, 2013; Maurer, Dardess, Carman, Frazier, & Smeeding, 2012). Failing to engage individuals who LEP, and people who have limited health literacy may exacerbate health care disparities, and reduce the potential of patient engagement to improve the health, and the healthcare experience of individuals from vulnerable BME populations (DeCamp, et al., 2015).

### **1.3 Population and Individual Characteristics**

Population and individual characteristics according to the Andersen model are comprised of three central sub-components: predisposing, enabling and need-related factors. Predisposing characteristic, are factors that exist prior to ill health (e.g. sociodemographic profile, e.g. age, gender, ethnicity, education, occupation, attitudes, knowledge, and beliefs), and are associated with access (Andersen, 1995). According to the model, enabling resources improve health outcomes, as they offer an individual support to facilitate access to appropriate health care. Enabling factors can be categorised at the individual (e.g. income, social support), and the provider level (e.g. physician-patient level). Need-related factors include subjective assessments about health, and the need for health care, or can involve more objective and measurable factors (e.g. chronicity, seriousness), which influence health behaviour and health outcomes. The following section aims to explore each of these

A qualitative study exploring the experiences of access and pathways to health care among BME community groups residing in Ayrshire characteristics in turn.

### **1.3.1 Predisposing Factors**

#### **1.3.1.1 Ethnicity and Health Care Access**

Various authors argue that some BME groups are particularly disadvantaged when it comes to accessing health care services and receiving equal quality of care, with reports of some BME groups receiving fewer procedures and poorer-quality care than those from White populations, and that these differences exist even after variations in socioeconomic factors, illness trajectory, or severity of disease have been adjusted statistically (Atkinson et al., 2001; McLean, Campbell, & Cornish, 2003; Nazroo, 2003b; Bhopal, 2007; Goddard, 2008; The Marmot Review, 2011; Williams & Wyatt, 2015). Earlier reviews of the literature exploring ethnicity and access found that BME communities experience inequalities in accessing essential health information, and services to meet their needs for prevention, prompt diagnosis, treatment, and care (Lanceley & Cox, 2007). There is, however, a trend in this body of work towards homogenising groups of people who are in fact diverse. The data sets are limited in terms of offering descriptive data, with minimal attention paid to critically evaluating, and reporting adverse effects of interventions (Berman, & Parker, 2002; Dixon-Woods et al., 2005).

#### **1.3.1.2 Ageing, Health, and Wellbeing**

One of the most significant factors contributing to the increasing pressures on health and social care in Scotland is the rising ageing population (Audit Scotland, 2016, pp. 5-6). It is estimated that there will be approximately 16,000 additional individuals aged 75 years and over between the period from 2021 to 2039; and by 2034, it is predicted that the population of those 85 years and older will have doubled (National Records of Scotland, 2015). Although the population in Scotland is ageing in general terms, “healthy life expectancy” (the number of years individuals may experience good health), has improved. Older people living

with co-morbidities (e.g. depression and chronic physical illness), often receive inadequate help when they access primary care (Chew-Graham, Baldwin, & Burns, 2004), and tend to be under-diagnosed and poorly managed (Wilson, Mottram, & Sixsmith, 2007). However, a study documenting older people's narratives about staying well and succeeding with life despite living with chronic ill health found a common narrative of "*keep going*" (Sofaer-Bennet et al., 2007; Richardson, Crime, & Ong, 2014). Richardson and colleagues (2014), undertook a longitudinal qualitative study to explore 'wellness and resilience' in a group of older people who were living with chronic joint pain, yet, considered themselves healthy. Participants described '*keeping going*' in body, mind and everyday life. For some participants "keeping going" was presented as an attitude. To illustrate, one participant (George), had a history of asthma, had only one lung, and was also living with osteoarthritis. George said:

*"...don't give up, keep going. Don't give up. Don't let it get on top of you, which for a lot of people it does..."*

(George)

Richardson and colleagues (2014), suggest that a starting point for health and social care provider is to work flexibly, and align their approach as a means of balancing their perceptions of an "*individual's frailty with an individual's embodied and lived experience*".

### **1.3.1.3 Knowledge, Attitudes, and Beliefs**

Previous research suggests that clinicians' attitudes, beliefs, and behavioural intentions are key to supporting patients' access to care, and to bring about sustainable HBC in high-risk patient groups (Sharples et al., 2016; Knowles, et al., 2015). Patients' knowledge, attitudes, and beliefs have also been found to exert an effect on access to care among BME groups (Scheppers, Dongen, Dekker, Geertzen, & Dekker, 2006). The results from the scoping

project which underpinned the present study (McKenzie, 2009), showed that younger Asian men residing in Ayrshire seemed to be knowledgeable about local screening services, primary and secondary care services, and felt able and confident to seek help if/when required. A barrier to accessing local sexual health screening services was a “*fear of standing out*”. When prompted to elaborate, one young man (Age: 25 years, pharmacology student) explained that “*being Asian...you stand out..*” in a predominately white community, which made him feel anxious about “*what folk would think...being seen in a sexual health clinic*”, resulting in this young man making a conscious decision not to “*...use local sexual health services...*” favouring “*...to go to Glasgow’s Sandyford Clinic*” if he needed to be “*tested*” or “*treated*”.

Younger Chinese and Indian participants raised and educated in Scotland felt confident about discussing their general and sexual health concerns and accessing general and sexual services. They were able to cite a range of locally available health and screening services. However, there were concerns expressed for the health needs of the “*elders in the community*”, as it was believed that they were in greater need of health care, and they experienced more barriers to accessing health services (e.g. lack of knowledge about health services, language difficulties, traditional beliefs about health, and health care). These concerns were echoed in the narratives of older Indian participants who were only aware of primary care services, and these older Chinese men were unforthcoming about discussing any concerns they had about their health. There remain gaps in understanding the pathways, and processes involved in access to health care among Ayrshire’s BME population.

#### **1.3.1.4 The Role of Employment, and Educational Status on Health**

Associations between a wide spectrum of health outcomes and unemployment have been reported in the literature (Scheppers et al., 2006; Bockerman, & Ilmakunnas, 2009), including



substance use and teenage pregnancy (Fergusson, Horwood, & Woodward, 2001), suicidal behaviours (Blakely, Collings, & Atkinson, 2003), and chronic ill health (Bartley, Sacker, & Clarke, 2004). While many of these studies report statistically strong associations between unemployment and poor health, establishing this as a causal relationship poses a greater challenge due to a reliance on observational rather than experimental studies (Bartley, Sacker, & Clarke, 2004). Joseph Rowntree Foundation (2016), reports that in 2015, 5% of White 16-24-year-olds were unemployed, compared to 29% from the Black communities, 24% of Asian, and 23% of those from 'other ethnic backgrounds'. Women with lower educational attainment have been found to receiving fewer Pap smears and mammograms (Ndikum-Moffor, Braiuca, Daley, Gajewski, & Engelman, 2013; Heberer et al., 2016), and women in lower paid work were found to have lower utilisation rates for influenza vaccination, cervical and colon examinations (Dubay, Ko, & Almeida, 2006). In addition, mortality from communicable diseases and HIV mortality rates among men are closely associated with education level (Garriga et al., 2015).

Vyas et al. (2012) found that older age and employment status were predictors of “*adherence*” to mammography guidelines in a rural population. The authors also described differences in health service use were related to differences in social, economic and political status. However, these studies failed to determine the primary drivers to unemployment (e.g. low self-efficacy, the role of intelligence, and personality traits), and the extent to which these factors influence the low uptake of screening services.

#### **1.3.1.5 Limited Health Literacy**

People living with long-term health conditions including depression, diabetes, stroke, and heart, kidney, and musculoskeletal disease are more likely to have limited health literacy (Adams et al., 2013; Rudd, Groene, & Navarro-Rubio, 2013). Healthy People (2010), defined health literacy as “*the degree to which individuals have the capacity to obtain,*

*process, and understand basic health information and services needed to make appropriate health decisions.*” Most definitions of health literacy include the following elements: 1. understanding relevant health information; 2. developing skills to manage risk and change relevant health behaviours; 3. understanding and recognising when help is needed; 4. navigate the health care system (Institute of Medicine, 2004; Schillinger, Sihota & Lennard, 2004). A systematic review of the literature found that limited health literacy is widespread and is regularly associated with people’s social circumstances (i.e. limited financial and social resources, low educational attainment), and ethnicity. Several studies within the review indicated that people with limited health literacy have a poorer quality of health and higher rates of hospitalisation (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005).

Limited health literacy has also been found to predict health behaviours (e.g. poor diet, smoking, and a lack of physical activity), independent of risk factors including age, education, gender, ethnicity and income (Bostock & Steptoe, 2012; Smith & McCaffery, 2010). Low health literacy is also associated with an increased risk of morbidity and premature death in older adults independent of age, socioeconomic position, cognitive ability and pre-existing illness (Al Sayah., Majumdar, Williams, Robertson, & Johnson, 2013; Loke, et al., 2012; Lowe, et al., 2013), poor quality jobs (Morrisroe, 2014), limited social support (Johnston, Jacobson, Gazmararian, & Blake, 2010), and help-seeking behaviour (Bourne, et al., 2010).

Assessing the evidence it could be argued that limited health literacy is a major determinant of health in terms of reducing opportunities for some people in vulnerable and disadvantaged groups to be fully equipped to engage in decisions about their health and health care (Institute of Medicine, 2004). This has the potential to undermine individuals’ ability to take control of their health, and the conditions that affect their health (Lee, et al., 2010; Howard, Sentell, & Gazmararian, 2006; Sahm et al., 2012). Some authors have argued that it is

essential to simplify health services and improve health education as a means of supporting people with limited health literacy (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). As a preliminary step, it is important to assess health literacy needs of specific populations, such as Ayrshire's BME communities, before adapting services which may have limited effect.

### **1.3.2 Enabling Factors**

#### **1.3.2.1 The Role of Income on Health and Access**

Clay (2001) suggests that higher income is associated with better physical and psychological health and wellbeing. The evidence from a range of studies consistently show that affluence is associated with perceptions of greater health, and with quantifiable good health (Wen, Browning, & Cagney, 2003; Deaton, 2003; Gregg, Jewell, & Tonks, 2010; Heath, Dirk de Graaf, & Li, 2010; Rowlingson, 2011). Conversely, low-income has long been associated with high-risk health behaviours, and poor health status (Syme & Berkman, 1976; Schoenbaum, Schoem, Nicholson, & Cantor, 2011). There is also strong evidence to show that mortality rates differ significantly between the rich and poor (Marmot, Rose, Shipley, & Hamilton, 1978; Marmot, Shipley, & Rose, 1984), with life expectancy differing on average by seven years more for people residing in the more affluent areas, compared to people residing in poorer areas (Marmot, 2010). Individuals living in poverty have been found to be four times more likely to assess their health status as fair or poor, than those who were not poor. Furthermore, the percentage of adults aged 55-64 with functional limitations also appear to increase as income level decreases, differing by almost six times between the highest and the lowest income levels (Minkler, Fuller-Thomson, & Guralnik, 2006).

Correlation analysis found an association between income inequality, health and social problems (Saunders, 2010; Rowlingson, 2011). However, Kenworthy (2010) found no correlation between income inequality and life expectancy, raising concerns about the choice

of datasets used to ascertain the extent to which income is associated with life expectancy.

These mixed findings suggest that further correlation analysis may be helpful in testing how sensitive the findings are due to different measures of income inequality, social stratification, and the treatment of outliers (Saunders, 2010). It is important to note that descriptive data of this type does not always use a sample representative of the larger population to collect data, thereby limiting any attempts to generalise the findings to individuals from BME groups that have dissimilar socioeconomic backgrounds (Costas et al., 2015). A major limitation of this group of studies arises from a lack of attempts to map causal pathway(s) that led to poorer health outcomes for some ethnic groups, to report individual-level risk factors (health behaviours), or to show any level of association between organisational barriers to health care services.

It is argued that people from BME communities residing in the UK with lower incomes are at greater risk of experiencing ethnic health inequalities (UK Government, 2007). Throughout the UK, BME communities are less likely than white people to be paid the living wage. The BME group most likely to be paid the minimum wage were Bangladeshi males (57.2%), followed by 38.7% of Pakistani males, 37% of Pakistani women, and 36.5% of Bangladeshi women (Brynin & Longhi, 2015). With the prevalence of poverty now on the rise, particularly among women and children, and those from vulnerable BME groups, increased attention must be paid to the risks to health that accompany unemployment and by association, poverty (Fitzpatrick & Cochrane, 2014). A more recent UK study found people from the Pakistani and Bangladeshi communities were at greater risk of experiencing 'persistent poverty', followed by Black African and Black Caribbean communities (Race Equality Foundation, 2016). In addition, there remain concerns about the disparity in funding allocated to services between the most deprived and affluent communities (a difference of 5%), which means that some social groups are not as able to access and use the full range of health services in Scotland than others (Scottish Government, 2015). There remains a

need in Scotland for more small-scale qualitative studies to explore the perspectives of BME community groups' understandings of the ways in which income impacts their perceptions of health and wellbeing, and to access appropriate health care services and resources.

### **1.3.2.2 The Role of Social Support**

Several types of social support have been found to relate to psychological adaptation to living with a long-term health condition (LTHC) (Section: 1.5.1), and negative support is associated with poorer adaptation (Jutagir et al., 2016). The type of support from family and friends, characterised by providing practical support (e.g. offering transport, interpreting, and advocacy) to enable access to health services and resources (Dixon-Woods et al., 2005); and offering reassurance, comfort, and assistance to problem-solving in the period following diagnosis of a chronic health problem (Schroevers, Helgeson, Sanderman, & Ranchor, 2010). For many, charity and third sector organisations act as an important resource where different types of support can be accessed (e.g. psychological support, informational and financial help, respite care, befriending) (MacMillian, Cancer Support, 2016; Maggie's Cancer Centres, 2016). Arguably, there is a perception amongst the rare disease community that public and major charitable funding bodies do not offer the same level of support for rare diseases, and that there is inadequate funding awarded for individuals and families, compared to more common conditions (e.g. diabetes) (RDUK, 2014).

A study investigating ethnic differences in types of social support offered after breast cancer surgery found that social support received from individuals from the same ethnic group (i.e. Ethiopians, Koreans, and Iranians), had stress-buffering effects and reduced depressive symptoms. The effects were not experienced as strongly among the Vietnamese and Irish participants. However, the authors suggest that the findings uphold the socio-cultural similarity hypothesis of social support (Jutagir et al., 2016). These results support findings from research exploring the association between ethnic density and health. This body of

work argues that ethnic density is associated with positive health behaviours (e.g. reduction in smoking during pregnancy) (Uphoff et al., 2016; George & Bassani, 2015). More work is needed to explore support offered across ethnic groups over time among people from BME communities living with LTHC residing in Scotland.

### **1.3.2.3 Physician-Patient Level**

#### **1.3.2.3.1 Health Communication**

Health communication encompasses several important elements that impact directly on patients, such as 1. developing and maintaining the therapeutic relationship (building trust, demonstrating empathy and a positive regard, confidence and supportive communication); 2. elicit information from the patient (e.g. medical history, symptoms experienced, patients' concerns, perceptions, and preferences); 3. provide information (e.g. seeking consent, shared decision making, and psycho-educational support), while ensuring patient understanding. Decisions about treatment options and referral to more specialised services are strongly influenced by the quality of communication between the doctor-patient, this is particularly important in older and disadvantaged patients (Heitanen, Aro, Holli, & Absetz, 2000; McVea, Minier, & Johnson-Palensky, 2000; Liang et al., 2002). This body of research suggests that improving the quality of health communication at the level of the patient-physician interaction can be an important opportunity to reduce inequalities in health. There remains a need to identify possible barriers to effective health communication among different patient groups, including individuals from various BME communities residing in Scotland.

## **1.4 Need-Related Factors**

### **1.4.1 Illness Perceptions**

Research investigating illness perceptions offer insights into how people perceive their health condition (e.g. serious, benign), symptoms experienced, treatment options, and attributions

made about disease onset, and subsequent illness trajectories (Leone et al., 2016). Knowles et al. (2017) found that illness status, illness perceptions, and coping influence health-related QOL by means of self-efficacy, anxiety, and depression. The authors argue that the results suggest that interventions aimed to improve an individual's QOL, should help develop and maintain an individual's self-efficacy, and the psychological processes underpinning illness.

Perceptions about illness have been reported as key determinants in the way people comply to medical treatment recommendations (Glasgow, Hampson, Strycker, & Ruggiero, 1997; Nwasuruba, Khan, & Egede, 2007). Earlier studies have examined variations in illness perceptions and self-management in relation to ethnicity (Barnes, Moss-Morris, & Kaufusi, 2004; Bean, Cundy, & Petrie, 2007; Nwasuruba, Khan, & Egede, 2007). However, the cited studies were cross-sectional in design, for that reason, it is not possible to determine the direction of effect in the reported associations, nor draw firm causal inferences from the findings.

Al-Smadi and colleagues (2016) conducted a systematic review investigating the differences in risk perception in patients diagnosed with coronary heart disease (CHD). The findings show that men and women differed in their perceptions of causality; with men more likely to identify key aspects of their health behaviour as the root cause than women. The review found that men had a stronger perception that their own behaviour had caused their illness than women. In addition, older patients had lower perceptions of the consequences and chronicity of their illness. This analysis concludes that some dimensions of illness perception vary according to predisposing factors, such as the age and gender of patients living with coronary artery disease. The complex interaction between perceptions as a need-related factor and predisposing factors should be noted. Indeed patients' interpretation of their illness and their health behaviour may be a product of their socio-cultural background, and their personal experiences (Atkin, Stapley, & Easton, 2010). The

complexity of illness perception and self-management has led to calls for a more focused and contextualised interpretation of the concepts (Atkin, Stapley, & Easton, 2010). It is argued here that more ideographic accounts are needed to understand the ways in which different patient groups, including those from BME communities, understand and make sense of their ill-health, and their perceptions of the need for health care.

#### 1.4.1.2 Illness Perceptions: Candidacy and Sense of Self

The concept of candidacy was originally applied to health care access for vulnerable populations (Gertler, Garn, & White, 1951; Blaxter, 1979; Blaxter, 1983; Williams, 1983), to understand the extent to which predisposing factors, exert an effect on the candidacy process (Dixon-Woods et al., 2005; Koehn, 2009), and to explore access and health service utilisation across a wide range of health conditions (Blaxter, 1979; Williams, 1983; Emslie, Hunt, & Watt, 2001a; Emslie, Hunt, & Watt, 2001b; Kovandizic et al., 2011). Dixon-Woods et al., (2005), extended the concept of candidacy, to include the ways in which the eligibility for medical attention and intervention is “jointly *negotiated between the individual and health service.*” The utility of the concept has also been used to understand the “*journeys through public services*” (MacKenzie, Conway, Hastings, Munro, & O'Donnell, 2013), to explore relational aspects of the doctor-patient relationship, and the importance of illness identities when accessing healthcare (Macdonald et al., 2016). The concept of identity is associated with individuals' motivation to define and express their self-identity (Pierce et al., 2003). Self-identity can be considered as the boundary between the individual and society as the individual develops a sense of self-identity through “*seeing themselves through the eyes of other*” (Clarke & James 2003; Pierce et al. 2003). Pierce posits that a sense of “*ownership becomes a symbol of the self*” as it satisfies the basic needs of self-identity (Pierce et al. 2003). The idea of ownership as a symbol of the self is a fundamental sociological concept (Clarke & James 2003). It is a dynamic process of identification which is grounded in an individual's self-identity. Within this framework, identification with a chronic illness or disease



state could be considered dynamic and emergent, as it changes as the individual reflexively makes sense of the label that self and others bestow upon him/her (Clarke & James 2003). Self-identity is subject to change when subjected to a life-threatening disease (Karnilowicz, 2011). Karnilowicz (2011), posits that the effects of illness may be debilitating, and confronting and the illness process often requires one to gain control over its effects by assuming some level of ownership. In a qualitative study of Scottish women's experiences of myocardial infarction (MI) (McKenzie, 2005), women experienced a threat to their identity post-MI. The women reflected on a change in their identity of who they are, who they were, and who they will become. One woman said:

"I always believed I'm superwoman, and I can do everything. It was like a reality check. You're mortal. It really brings your mortality into being. It's frightening."

Surviving an acute life-threatening event (MI) caused all of the women in this study to feel anxious, fearful, and to experience an awareness of their mortality, a change in how they perceived themselves, and their ability to maintain a control over their lives, their health, and their ability to cope. Reflecting on why she felt so threatened when family members offered to care for her, Margaret said:

"I think that's what I am, it's who I am. And when people take that control away, I am lost, I feel as if I have lost me...I was the one in control, and suddenly, everyone wanted to take control of me"

In the immediate aftermath of experiencing an MI, this group of women experienced a deep sense of loss of control, which had a profound impact on their personal identity and

sense of self. There was also a tangible lack of agency (Diehl, Owen, & Youngblade, 2004), in that the women felt unable to assert themselves, to experience competence, achievement, power and mastery in their environment. Under these circumstances, establishing psychological ownership, was problematic and in some instances may be considered beyond this group of women's reach. One of the primary strengths of this study was the use of face-to-face, semi-structured individual interviews. This study had some limitation. The results could not be generalised out with the study participants. In addition, the study may have been at high risk of performance bias, as a minimum effort was made to evaluate the extent to which the findings were a consequence of the interviewer effect.

### **1.4.3 Risk Perceptions and Need for Screening Services**

#### **1.4.3.1 Prostate Cancer Screening**

Despite prostate cancer (PC) disproportionately affecting more Black African and Caribbean men than White men, PC perception of risk is low in these groups (Pedersen, Armes, & Ream, 2012). Pedersen and colleagues (2012), found that men's PC testing and treatment were perceived as a threat to men's sense of masculinity. In addition, a high level of mistrust of the health care system, limited access to health care and lack of trusting relationships with health professionals was found. The authors argue that the factors impacting on Black men's risk perceptions of PC may contribute to late PC diagnosis and should be taken into account when communicating with Black men seeking prostate care. However, little is known about other factors that may prevent Black men, and men from other BME groups in Scotland from seeking informational support, or accessing PC screening services.

#### **1.4.3.2 Breast and Cervical Cancer Screening**

A qualitative study which set out to understand the perceptions of preventative breast and cervical screening found that non-symptomatic Chinese and South Asian immigrant women did not feel the need to get screened in the absence of symptoms. Among women who

experienced cyclical breast pain, and 'lumpy breasts', a greater perception of the need for screening was found. However, all of the women reported feeling uncertain about the role of mammography in addressing these symptoms (Hulme et al., 2016). Anxiety and uncertainty about exploratory investigations for abnormal uterine bleeding or pelvic pain were found, and a high degree of ambiguity about the purpose of PaP screening tests was reported. Some women in this study stated they delayed Pap screening tests until they perceived a need for an investigation and the most common reason for access and utilisation of Pap screening services were concerns about symptoms experienced. There remains a paucity of qualitative research exploring breast and cervical cancer risk perceptions of women's from various BME groups, and the relative role of these on the perceived need for screening services.

## **1.5 Health Outcomes**

### **1.5.1 Public Health Concern: Long-Term Health Conditions**

Long-term conditions (LTHC) are a major public health concern, which presents a challenge to the sustainability of health care services (Alliance Scotland, 2015). The term LTHC refers to any health conditions which persist for 12 months or more (Scottish Government, 2015), which may require ongoing management and support from health and/or social care services over a period of years or decades (Scottish Government, 2015). The increasing prevalence of LTHC is associated with a greater need for health care, with higher expectations of care (Richmond Group, 2012), and a greater risk of developing complications and premature mortality (Ward, Schiller, & Goodman, 2014; Barnett et al., 2012; Salisbury, Johnson, Purdy, Valderas, & Montgomery, 2011). People living with LTHC are on average, two times more likely to be admitted to hospital, will stay longer in hospital, and are at increased risk of experiencing psychological problems (e.g. depression, anxiety), compared to people who experience acute health care needs (Goodwin, Curry, Naylor, Ross, & Duldig, 2010; Alliance Scotland, 2015). The majority of people who need long-term residential care are more likely

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to have complex needs from multiple co-morbidities (Scottish Government, 2015).

The challenges people experience vary widely depending on personal circumstances, the presence of co-morbidities, uncertain illness trajectories, the capacity to self-manage, and the need for a regular source of care (Coulter, 2011, pp. 86; Hibbard & Greene, 2013). An individual's concerns, focus, and goals also vary and may often extend beyond the health condition, particularly for people living with multimorbidity or experience regular health crisis (Hibbard & Greene, 2013). There is a need to build qualitative data sets of BME community groups' experiences of living with long-term health conditions as a means of identifying and addressing possible unmet health care needs, and/or need for support.

## **1.6 Health Behaviours**

### **1.6.1 Compliance and Health**

Compliance to medication and medical treatment can be influenced by a lack of knowledge about the goals of therapy (e.g. lowering blood pressure) (NICE, 2015). Compliance is important for improved general health, and QOL (Bezabhe et al., 2014). Poor compliance to HBC interventions, such as linking medication taking to daily activities, or using a medication reminder system, or a pill organiser, have been found to be associated with treatment failure, and poorer health outcomes (Fisher, Fisher, Amico, & Harman, 2006; AIDSinfo, 2014). A qualitative study conducted by Langu and colleagues (2015), found a mismatch between HIV patients and physicians' expectations and responsibility for compliance with antiretroviral therapy (ART). The findings show the most commonly cited expectation among patients was that ART would "...*help me live*", "...*not to make me feel sick...*", "*to be easy to take...*", "*not to show on the outside what I have on the inside*". The physicians' expectations of ART include: "*to reduce HIV viral load*", "*to increase CD4 cell count*", and "*to have minimal impact on the proper functioning of other organs*". As far as responsibility for ART adherence, 56.6% of participants felt solely responsible, 20% consider the doctor to be responsible, and 16.6% situated responsibility for adherence with others (i.e. friends, family, and spouse);

6.6% did not respond to this question. Conversely, the physicians placed complete responsible for adhering to ART with the patient. This mismatch in expectations and responsibility has the potential to compromise optimal adherence, and result in possible poorer health outcomes for this group of patients living with HIV (Largu, Dorobat, Astarastoe, & Manciu, 2015). Still, little is known about the expectations and perceptions of ART compliance among Scotland's BME community groups.

### **1.6.2 Help-Seeking Behaviour**

The concept help-seeking behaviour (HSB) is an important device for exploring and understanding factors underpinning patient delay and prompt action across a variety of health conditions (Galdas, Johnson, Percy, & Ratner, 2010; Cornally & McCarthy, 2011; McKenzie, 2009). The term is used to describe both illness behaviour (e.g. accessing health care system; self-help strategies, and ignoring symptoms), and engaging in health behaviour (e.g. exercise, healthy eating, and accessing preventative screening services), as a means of maintaining health, preventing ill health, and/or to reduce the effects of chronic disease. Cornally and McCarthy (2011), described HSB as a complex decision-making process prompted by a *"problem that challenges personal abilities"*. According to the literature, the process is characterised by the following attributes: 1. problem focused, 2. intentional action, and 3. interpersonal interaction. In an earlier study, Mechanic (1995) suggests that HSB is influenced by a wide-range of causes, including biological predispositions, learned patterns of response, attributional and situational influences, and specific characteristics of the health care system that prevents full and equal access to care for some community members.

#### **1.6.2.1 Gender Differences in Help-Seeking Behaviour**

There are a number of studies which look at the gap between the onset of symptoms related to acute myocardial infarction (MI), and the decision to seek treatment. One review of over 100 studies of treatment-seeking delay reported that women (predisposing factor) had longer

delays than men (predisposing) before seeking help when experiencing symptoms of an MI, but there were no differences between women and men when experiencing symptoms of stroke (Moser et al., 2005). Lefler and Bondy's (2004) meta-analysis of delays in treatment-seeking reported that larger-scale studies with greater statistical reliability were most likely to report longer delays in seeking treatment for women than men. One study suggested that, while men and women were equally likely to delay, the time delay before seeking treatment was longer for women than men (Johansson, Stromberg, & Swahn, 2004). However, Oliver, Pearson, Coe, & Gunnell (2005), found that men were less likely than women to say that they would seek help (OR=0.78, 95% CI 0.72–0.88,  $P<0.001$ ), and were also less likely than women to have sought some form of help (OR=0.66, 95% CI 0.56–0.77,  $P<0.001$ ). Research also suggests that there are differences between women and men in where they seek help and why they delay. To illustrate, women were more likely to consult a GP first rather than seek emergency help (Leslie et al., 2000). Differences in the reasons for the delay in emergency help-seeking include women's belief that they are less likely than men to be having an MI, and that women often attribute their symptoms to a less threatening cause, or to a pre-existing health condition (McKenzie, 2009). Women are also more likely to say they wanted to avoid worrying others; they attempt self-treatment more often and are also more likely to turn to a friend or family member for advice (Walsh, Crumbie, & Watson, 2007). Patterns of HSB among Ayrshire's BME communities are not clearly understood. Through exploring lived experiences of access, it is hoped the present study will be able to offer insights into the HSB, and pathways to health care among the men and women who took part in this study.

### 1.7 The Present Study

There is a growing body of evidence exploring the health care needs of BME groups in England, yet there remains a paucity of qualitative studies to exploring the experience of Scotland's BME community groups' access to health care. The present study supports the

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shift of interest within the health research community to understand pathways to health care, and “*journeys through public services*” (MacKenzie, Conway, Hastings, Munro & O'Donnell, 2013). The present study is also concerned with the processes through which individuals make sense of their experiences of access (Chapman & Smith, 2002; Smith et al., 1997), and the meanings participants ascribed to those experiences.

### **1.7.1 Objective of the Present Study**

The main objective of the present study was to gain insights into the perspectives of BME community groups' experiences of accessing general and sexual health care services in Ayrshire.

## Chapter 2

### Methodology

#### 2.1 Design

To address the issue central to this study, interpretative phenomenological analysis (IPA) has been employed. IPA is concerned with understanding the person-in-context, and exploring individuals' relatedness to the world (Boydell, Fergie, McDaid, & Hilton, 2015). IPA is also concerned with novelty, and complexity, as it seeks to find commonalities and differences between participants' accounts (Rodriguez, 2011), and to ascertain if there are shared understandings at both the individual and the group level (Rodriguez, 2011). The classification of emergent themes across many qualitative studies shows that shared experiences become apparent when a phenomenon is not group-based (Patton, 2002, pp. 339). Nevertheless, Patton (2002, pp. 340) argues that the "*social and concurrent*" nature of group experience may involve greater impact on shared meanings than in otherwise isolated experiences of a phenomenon. To illustrate, a descriptive study (Hunter, Coventry, Mendes, & Gunfeld, 2009), exploring the cognitive and behavioural components of hot flushes and night sweats (HF/NS) in 35 female breast cancer survivors post-treatment, found that the women's reflections revealed shared strong negative beliefs about a change in sense of self that seems to be more pronounced in social situations. Further reflections offered insights into why the women avoided social situations, the most commonly shared reasons were feeling "embarrassed" and "anxious" about having a hot flush when they are in a social situation. The women's shared experiences of HF/NS and collective reflections strengthened the study's findings.

#### 2.2 IPA Theoretical Orientation

IPA offers a methodological framework and a comprehensive procedural guide to conducting qualitative research. IPA has its roots in psychology and was developed as a psychological



methodology concerned with the detailed exploration of individual experience (Smith, 1996).

IPA is theoretically grounded in phenomenology, hermeneutics, and idiography (Smith, Larking, & Flowers, 2009; Merleau-Ponty, 2012, pp. 53-80). Phenomenology is concerned with attending to the ways things appear to individuals in their experiences (Larkin, Watts, & Clifton, 2006). It aims at identifying the essential components of experiences which make them distinctive or distinguishable from others, rather than describing experiences according to a predetermined conceptual, or categorical criteria (Smith, 2008). This involves “*bracketing off*” preconceptions regarding the topic under investigation, to allow the researcher to focus on interpreting participants’ narratives. This facilitates the development of ‘*the novel, the interesting and the unexpected*’ (Kirkham & Smith, 2015). This means making sense of the “*phenomenon experientially*” and then connecting the interpretation back to the relevant and resonant theoretical and/or empirical work in the discussion.

Hermeneutics is grounded in the work of three prominent philosophers (Heidegger, Ricoeur, & Gadamer), and is concerned with the meanings of human experiences as they are lived, with particular attention to the communities of meaning (cultural, sub-cultural, linguistic, religious, gendered) (Habermas, 1994). Thus, IPA researchers attempt to understand what it is like to ‘*stand in the shoes*’ of participants (while acknowledging this is not always possible) and, through interpretive analysis, “*make meaning understandable by translating it*” (Smith, 2011a). This means that IPA is a dynamic process, with the active role of the researcher who influences the extent to which they gain access to participants’ experiences, and how, through analysis, they make sense of participants’ “*personal world*” (Smith, 2011b). The analytical process in IPA is often described in terms of a double hermeneutic or dual interpretation process because 1. the participants make sense of their experiences; and, 2. the researcher tries to interpret the meaning ascribed to those experiences (Smith & Osborn, 2008), from the participants’ perspective. Yet, at the same time formulates critical questions, such as 1. Is anything meaningfully being said here, which was not intended? 2. Do I have a

sense of something going on here that the person himself/herself is perhaps less aware of? (Pietkiewicz & Smith, 2014). IPA studies may, therefore, contain elements of both types of interpretation, making the analysis richer and more comprehensive. Another theoretical orientation which IPA relies upon is idiography. This refers to an in-depth analysis of single cases and examining individual perspectives of study participants in their unique contexts (Pietkiewicz, & Smith, 2014). The fundamental principle behind the idiographic approach is to explore every single case (Smith, Harre, & Van Langenhove, 1995), which allows for specific statements to be made about study participants because the analysis is based upon the detailed case exploration. The analytic process starts by an attentive exploration of an individual's experiences, thereby producing a case study, before moving on to the second case, and so on. This idiographic commitment continues to include all cases, until themes are generated in the analysis and exemplify them with individual narratives (how individuals tell their own story), comparing and contrasting them (showing similarities and differences) between the study participants' experiences, knowledge, and understandings.

### **2.2.1 IPA: Practical Procedural Guide**

IPA is a research tool used to explore shared beliefs, values, thoughts, feelings and experiences; offering a comprehensive, ecologically and ethically sound qualitative method. These facets are particularly useful for the present study, given the paucity of health information about Ayrshire's BME groups' experience of accessing and utilising the health care system. IPA involves a two-stage interpretation process whereby the researcher attempts to facilitate reflective and reflexive process to enable participants' to tell their story in their own words (Smith, Flowers, & Osborn, 1997), then analysis aims to interpret the ways in which participants make sense of their experiences (Pringle, Drummond, McLafferty, & Hendry, 2010). IPA offers an adaptable and accessible approach to phenomenological research intended to give a complete and in-depth account that privileges the individual (Pringle, Drummond, McLafferty, & Hendry, 2011). It enables health psychologists to access,

perceive and understand the experiences of participants, which can be used to influence and contribute to theory (Flowers, 2006). It is the individuals' perspective and understanding of the issues under discussion that constitutes the "analytic component" within much of qualitative research. It is acknowledged that individuals may hold a number of conflicting views on the same issue, based on equally valid rationales. Therefore many qualitative researchers attempt to 'sample shared understandings' and experiences by recruiting a diverse range of interviewees' (Flowers, 2006).

Willig (2001) suggested that IPA's status encompasses a developing approach which allows researchers more scope for creativity and autonomy. Smith (2004) suggests a number of ways in which IPA research might develop, including micro-textual analysis, increasing analysis of the single-case study, and recruiting different participant groups and ways of collecting data. An increased focus on the individual case might address concerns relating to preservation of the richness of individual accounts (Collins & Nicolson, 2002), and is in line with increased efforts within the NHS to make greater efforts to acknowledge the voices of service users. IPA is entirely congruent with the increased interest in PCC approaches to research and health care (Wilkie, 2013). In addition, Smith (2004) set a challenge for IPA researchers to reflect on emergent core constructs in IPA and the relationship between IPA and other phenomenological approaches.

## **2.2.2 Relevance of IPA to Health Psychology**

IPA has traditionally been applied to problems in health psychology (Smith, Jarman, & Osborn, 1999), but is increasingly becoming more popular in other disciplines (Smith, 2011a). IPA has been applied to study a range of different topics, including hot flushes and night sweats in a breast cancer population (Hunter, Coventry, Mendes, & Gunfeld, 2009); myocardial infarction and coronary heart disease (McKenzie, 2005; 2008); patients' illness experience, human reproduction, addiction, and therapist's experiences (Smith, 2011a).

More recently IPA has been used to explore chronic pain (Kirkham & Smith, 2015); adolescent boys with autism spectrum disorder, and their experience of sexuality (Dewinter, Parys, Vermeiren, & van Nieuwenhulzen, 2016); parents who are currently providing care for a child with a life-limiting condition (Collins, et al., 2016); post-traumatic growth in adult survivors of child sexual abuse (Hartley, Johnco, Hofmeyr, & Berry, 2016); fathers of children with congenital heart disease (Gower, Higgins, Doherty, & McCormack, 2016); patients living with cancer (Bar-Sela, Danos, Visel, & Mitnik, 2016), and anorexia nervosa (Kolnes, 2016). A core finding between these studies demonstrates not only the central role of the individual but also the social and concurrent nature of shared experiences within and between different groups of people as they live with challenging life circumstances (Patton, 2002, pp. 339-341). In addition, theoretical links were made between these findings and existing literature while clinical implications include the need for patients, and family members to be involved in health decision-making; and to respect their need to maintain control. In addition, IPA can be useful to examine how various groups construct their identity, the meanings they attribute to social roles, and how they perceive the social world (Smith, 2011a).

### 2.2.3 IPA: Key Components

IPA can be considered an ethically valid research method as it endeavours to respect participants as being the experts with regards to their own experiences. Smith (2004) describes IPA as having three major strands in that it is idiographic, inductive, and interrogative. IPA is inductive as it appreciates that latent issues are not always transparent to the researchers, and its 'bottom-up' epistemology allows for unanticipated findings to emerge without being constrained by any pre-identified hypotheses or *a priori* assumptions' (Flowers, 2006). This calls for the analyst to be reflective at the analytic stage to reduce any possibility of bias or taking too narrow a perspective (e.g. using theoretical models to conceptualise findings, or by relying on limited knowledge or experience). This is achieved by the analyst returning to the data (and making use of field notes) to check for content, tone,

IPA is not concerned with generating hypotheses, but rather to generate broad research questions that allow for full rich data to be gathered and explored (Smith, 2004). Further, IPA is interrogative in that it aims to add to the existing literature, and can be used to offer an alternative perspective, giving a voice to marginalised and isolated groups within society. The present study aimed to tap into participants' natural propensity to reflect, as this creates the opportunity for an active engagement in the process of interpreting and making sense of their own experience (Chapman & Smith, 2002; Smith et al., 1997). In doing so, participants begin to formulate their own biographical account that helps them to understand their world more fully (Flowers, 2006). This methodology is fitting for the present study, given there is a paucity of qualitative literature exploring access to care among Ayrshire's BME community groups.

Critics argue about how to assess the validity of qualitative studies such as this one (Sandelowski, 1993; Dixon-Woods et al., 2005; Bardour, 2007). To address this concern, Yardley (2000) proposed comprehensive principles from which to assess quality (Figure: 1). Integral to the design of this study are these guiding principles, which were also used by the researcher to facilitate a critical evaluation of the methods used (Chapter 8: Section: 8.3.2).

#### **2.2.4 Ontological & Epistemological Stance**

Underlying the researcher's ontological and epistemological stance are a set of ethical values that guided and directed the approaches used in the present study. Griffiths (1998, p. 44), argues that a consequence of this stance is a "*radical uncertainty about the very possibility of knowledge and truth*". Rather than viewing this as a limitation, the researcher argues for the value of uncertainty in qualitative research. To illustrate, IPA calls upon the

researcher to assume a novice perspective, as this opens up the opportunity to try to understand the perspective of another, and allows participants the opportunity to assume the role of the expert. Aligned to the researcher's ethical stance, is a critical perspective, which takes account of, context, differing perspectives, and bias. Researchers argue that bias is unacceptable. It is argued here that bias is unavoidable. Being aware of the possibility of introducing a risk of bias into this particular work, the researcher strived to work as transparently as possible, making every effort to minimise, and to address the risk of bias. This stance can be considered in itself to be biased, and challenges the view of "*value-free knowledge*" and understanding, and ascribes to the notion that it is possible to understand and make sense of another's experiences, while, at the same time, being aware of what the researcher brings to the equation. This was achieved by working reflectively (Schon, 1983), and reflexively (Greenbank, 2003), which allows qualitative researchers to respond critically and sensitively (Griffiths, 1998, pp. 133).

<b>Figure 1.</b>  <b>Guiding Principles</b> (Yardley, 2000)	Sensitivity to Context
	Commitment and Rigour
	Transparency and Coherence
	Impact and Importance

## 2.3 Inclusion Criteria

Individuals residing in Ayrshire who identified themselves as either Black or from a Minority Ethnic group which could be regarded as cultural, racial, linguistic, geographical or physical traits were invited to take part in this study. There was no upper age limit. The lower age limit was set at 16 years of age, based on demographic information provided by the Census (2001; 2011).

### **2.3.1 Exclusion Criteria**

The following ethnic groups were excluded from this study 1. White Scottish, 2. White-Irish and 3. White-British, based on the demographic profile in Ayrshire outlined by the Census (2001; 2011), and the document produced by Ayrshire Race Equality Partnership (2005).

## **2.4 Sampling Methods**

IPA sampling tends to be purposive and broadly homogenous as a small sample size can provide a sufficient perspective given adequate contextualisation (Smith & Osborn, 2003). In this respect, IPA differs from other methodologies, such as grounded theory, as in IPA the aim is to select participants in order to explore a particular research question and to develop a full and rich interpretation of the data. In contrast, Grounded Theory uses theoretical sampling, which aims to keep collecting data in the light of the analysis that has already taken place, until no new themes are emerging. Thus, while grounded theory seeks to establish claims for the broader population, IPA studies tend to be more concerned with examining divergence and convergence in smaller samples.

### **2.4.1 Snowballing Sampling Methods**

Snowballing sampling is a useful non-probability sampling method for the recruitment of members of hard to reach populations (Babbie, 2001). Snowballing sampling methods can also be understood as a means of collecting data about members of a specific population. This process is reliant on the help of individuals to provide key information to locate other members of the population whom they know (Atkinson & Flint, 2001). Critics argue that snowballing sampling is limited in terms of not recruiting a representative sample. It is argued that snowballing sampling was the most appropriate method available to contact hard to reach BME community members, who do not access local health care services in Ayrshire. It is acknowledged by the researcher that the snowballing sampling process is subject to selection bias (Chapter 8: Section: 8.3.4). In an attempt to reduce the risk of selection bias,

participants were selected using pre-defined criteria to avoid confounding results.

In addition, it is argued that this study had a strong methodological design, and the methods used were appropriate, transparent, and evidence-based.

#### **2.4.2 The Sampling Process**

In the initial stage of sampling, key members of BME community groups (Mr Chan, Chairperson for the Kat O Chinese Association; Mr Arjit Singh Uppal, chairperson, Ayrshire's Sikh community Group; Oi Kwan, Chinese Women's Group; Mr Martin Katongo, Black African Minority Association, and Parnee Wongpakdee), were contacted to establish formal communication with potential participants. Initially, these key community members were contacted by letter and a week later by telephone. They agreed to establish contact with individual BME community members, at formal community group meetings; informing potential participants that we wished to explore the perspectives of BME community groups' experiences of accessing general and sexual health care services (Chapter 1: Section: 1.7.1).

Potential participants were offered a copy of the information sheet (Appendix: 3), explaining the purpose of the study, the procedure, issues regarding confidentiality and anonymity, and information about the main topics to be discussed in the interview. Individuals who expressed an interest and consented to take part were invited to attend an interview at a venue of their choosing (e.g. home, a community centre in Ayrshire, or workplace). Selection of participants focused on obtaining a sample that equally represented men and women from all BME groups throughout the three local authorities (East, South, and North) in Ayrshire. All participants who expressed an interest in the study were recruited.



## 2.5 Characteristics of the Sample

The present study aimed to be inclusive, and not to discriminate against any individual from Ayrshire's BME community groups who wished to take part in the study. We, therefore, wished to recruit male and female participants from a range of age groups and long and short term residence in Scotland. It was hoped that by capturing different perspectives we would be able to offer a more comprehensive overview of the lived experiences of Ayrshire's BME community groups. The resulting sample included 11 participants (n = 5 men, n = 6 women) (Appendix 2; Table A). However, an unanticipated number of individuals attended, aware that interviews were being conducted, made an impromptu decision to listen and observe; whilst others contributed to the discussion (Chinese groups). As much as this created a challenge in terms of keeping the interview on track, it also offered the opportunity to respectfully manage the situation by acknowledging comments, while remaining focused on the interaction with the primary interviewee. As the interviews were audio recorded and transcribed verbatim, it was determined (by the researcher, and Professor McVittie, Director of Studies), during the analysis stage, that the additional comments did not add anything of value, and had no relevance to the context of the interview, and were therefore eliminated in the earlier stages of analysis.

At the time of the interview, all of the 11 participants were living in one of the three local areas in Ayrshire, Scotland. The interviews were conducted by the researcher in a variety of locations (e.g. within participants own homes, within community venues, in a restaurant, shop premises, in a portakabin, and one interview was conducted over the telephone). The final sample included five men (age range 32 – 65; mean age = 52.4 years) and six women (age range 27 – 60; mean age = 47.67 years). Of the five men, two were from the Indian Sikh Community, one was from the Black African community and two were from the Chinese community. Of the six women interviewed, one participant was from the Thai community, one was from the Polish community, two were from the Indian Sikh community and two were

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## 2.6 Saturation

Data saturation was first defined by Glaser and Strauss (1967), as the point at which “*no additional data are being found whereby the [researcher] can develop properties of the category.*” Failing to achieve saturation has major implications for the content validity, and reliability of the findings, with wider implication for the credibility of qualitative research (Tay, 2014). The definition of saturation adopted for the present study was that no new themes, findings, concepts or problems were evident in the data. Critically, the concept and claim of saturation are often mentioned in qualitative studies, yet, most fall short of explaining what saturation entails, and how saturation was achieved (Bowen, 2008). The present study aimed to chart the process of saturation, from sampling and data collection (Chapter 2, Section: 2.6.1), to data analysis (Section: 2.8), and theoretical saturation (Chapters: 3 – 8).

### 2.6.1 Saturation: Sampling and Data Collection

To ensure that recruitment and data collection saturation had been achieved, all BME community groups across the three local Ayrshire district council areas were contacted and invited to take part in the study. All BME community members who came forward for interview were included in the study. The recruitment of possible prospective participants was extended for a further month (while interviews were being transcribed). No new participants presented for an interview during this extended period of time. The time allocated from data collection (Chapter 2: Section: 2.7), ranged between 1– 2 hours (Appendix: 4), which allowed for intensive, face-to-face interviews to be conducted with 11 participants. Consistent with the idiographic approach, small sample sizes are commonly advocated for IPA studies (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008). There, however, remains debate in the qualitative literature about what constitutes sufficient data (Creswell, 2013), with some authors arguing that different sample sizes depend on the

qualitative approach employed (Guest, Bunce, & Johnson, 2006). Guest and colleagues (2006) argued a case for six participants for phenomenological studies, to approximately thirty-five for grounded theory, to numbers up to and exceeding 100 for “qualitative ethology studies”. Although the present study recruited 11 participants, which exceeds the sample required for IPA analysis, the sampling strategy used was less concerned with the size of the sample but was more interested in the appropriateness and adequacy of the sample (O'Reilly & Parker, 2013).

## **2.7 The Interview**

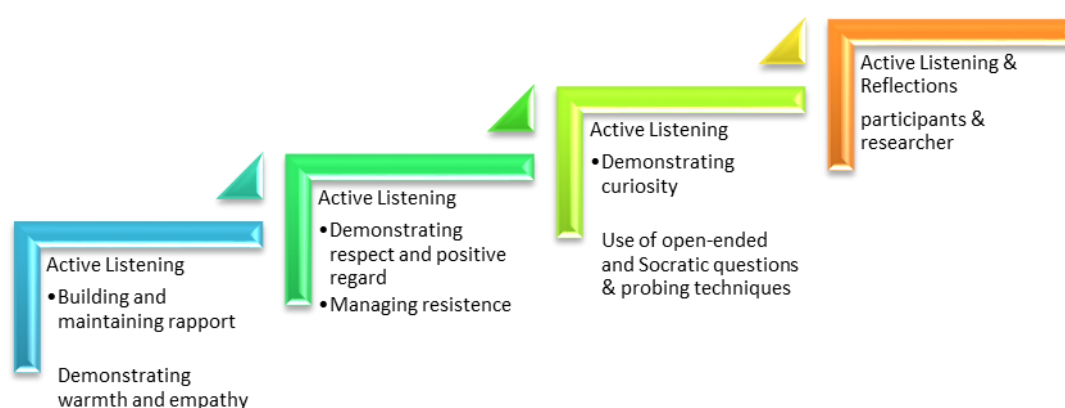
Consistent with IPA a semi-structured interview schedule was developed (Appendix: 3). This method was useful in terms of gaining a detailed understanding of participants' beliefs, perceptions and lived experiences of a particular topic (Smith, 1995). The interview was facilitated by using a series of open-ended questions relating to the experiences of using the health service and to explore potential barriers to accessing services in an attempt to identify the needs of the various BME communities. The interview style was flexible and non-directive and a process of reflecting, and probing (e.g. 'could you tell me more about ...'), allowed interesting points to emerge during the interview, which was followed up and summarised to explore more fully participants experiences, whilst checking for clarity and understanding.

The interviews were transcribed verbatim and analysed to identify recurrent themes. Field notes were taken to pick up on any nuances during the interview process and referred to during the analysis stage to check for context and clarity. From the first contact to the end of the interview the researcher worked to build and maintain rapport by demonstrating respect, interest and an appropriate level of warmth and empathy and strived to reduce any potential for resistance (e.g. respecting each communities cultural norms).

### 2.7.1 Clinical Interviewing Skills

In addition to employing traditional IPA interview methods outlined above, a range of established verbal clinical skills was integrated to facilitate disclosure of sensitive but core issues, aimed at helping participants feel their views were important and were understood (Figure: 1). In the initial stage of the interview, open and closed questions were used to encourage participants' active engagement in the interview process. As the interview progressed, Socratic questions were used to explore more fully personal assumptions and conflicting views. Socratic questioning techniques encourage a process of helping people explore more fully their own perspective, so as to gain a deeper understanding of their value systems, emotions, rational and practical realities. Integrating Socratic questions offered participants the opportunity to reflect on their experience of health care. The use of reflections resulted in participants gaining insight about their values and belief systems while summarising techniques offered structure to what participants said by ordering the main points of his/her account. This helped gain clarity about perspectives, thoughts, and feelings (Krawford, 2011).

**Figure 1 Clinical Interviewing Skills**



(Rogers, 1951; Miller & Rollnick, 2002)

This process requires the interviewer to follow a non-directive line of enquiry, so that the interview was relaxed and informal, while created opportunities to meander and deviate. This technique enables a spirit of collaboration, with participants feeling able to take control of the direction of the interview and to take a fresh look at their experiences and understandings. Working in this way upholds the guiding principles of IPA, which encourages researchers to adopt an attitude of curiosity, to be receptive and comfortable with asking questions from a place of naivety, and a lack of knowledge (Smith, 2004; Flowers, 2006). This process works in parallel with active listening techniques which require the interviewer to closely observe participants' non-verbal cues, whilst encouraging free expression (Trower & Jones, 2008).

The approach used throughout the interview was non-judgemental and reflected an unconditional acceptance of participants' accounts. That is to say, there was an acceptance of participants' views, regardless of what was said, in a non-challenging way, which helped the researcher to explore accounts in a spirit of curiosity. Being mindful to demonstrate an unconditional positive regard for participants created a safe environment and ensured that individuals felt valued and respected. In addition, the researcher put aside her own opinions (bracket-off), in an attempt to be as open as possible to gain a deep, unbiased understanding of participants' accounts. By communicating unconditional acceptance the researcher was more able to be totally authentic and genuine, qualities that have been previously reported to underpin sincerity, empathy, and acceptance (Rogers, 1951). It is argued that the open invitation to talk, with no constraints on what participants wished to talk about, within the boundaries of the research topic, allowed for a full exploration of participants' experiences (Chapter 3 to Chapter 6).

Integrating clinical interviewing skills (Figure 1), allowed for a more flexible way of working, and created the opportunity for participants to guide and direct the interview. This allowed

the researcher the opportunity to follow participants' interests and concerns more fully. This, in turn, helped to maintain rapport and to establish a more natural flow of the conversation, which led to gaining full and rich data. Every effort was made to reduce any signs of resistance. This was achieved by the researcher remaining aware of her verbal and non-verbal communication (e.g. changing her tone of voice), using reflections and affirmations to offer feedback and to support participants. Every effort was made to reflect during the analytic phase, and return to the original participants' accounts to ensure that they were themed and coded as the participants' intended. This called for careful and detailed analysis and reflection. This was only really problematic in terms of time, and limited financial resources.

## **2.8 Data Analysis**

IPA draws from various philosophical and epistemological perspectives, each offering a range of strategies which can be implemented at various stages of analysis. The idiographic component of IPA is used to guide the researcher during the analysis stage to focus on one participant's narrative at a time until saturation has been achieved, before moving onto the second participant's account. This process continues until all participants' accounts have been explored in full. When all the accounts have been thoroughly examined, attention is then focused on cross-case analysis and coding emergent themes; with the emphasis on exploring each case for convergence and divergence. This process results in enabling the reader to clearly see the themes that have emerged from the data, and to gain insights into shared lived experiences of participants

Preliminary analysis was conducted line-by-line, allowing for a greater engagement with the data, and to assert that analysis was firmly grounded in the data. The data was initially explored using an open coding system, to establish tentative relationships between emergent categories. Through a continual process of asking questions of the data, reflecting

(on what was, and, was not understood), coding, and re-coding of the data, it became possible to find supportive evidence and discrepancies within and across each transcript. Through this process, new connections, and categories emerged, which helped to gain a deeper understanding of participant's experiences, and of their perspectives. This exhaustive process gives rise to data reduction, revealing the extent to which there were very specific areas of convergence and divergence within, and across participants' accounts (Chapters: 3 – 6).

### **2.8.1 Analysis: Four-Stage Process**

The analysis closely adhered to the four-stage process described by Smith Larking, and Flowers (2009). In the first step, the author read the primary transcript a number of times in order to become familiar with the data. Any significant or interesting initial comments were recorded during this reading. Secondly, initial notes were transformed into emerging themes while paying attention not to overstate relations between the participants' own words and the researchers' interpretations. During the third stage, the emergent themes were examined for patterns and connections and clustered according to conceptual similarities. These clusters were subsequently labelled according to the conceptual nature of the themes in each cluster. Next, a table of themes was produced and sub-themes were nested with supporting quotes from the participant. Quotes were coded (e.g., D: David/5: page number/C: quote 3 on page no: ..) to safeguard the possibility of revisiting the transcript to check the context of the extract. Transcripts for the next ten participants were then read and subjected to the same analytic process. When considering individual cases during data analysis in an IPA study, we are inevitably influenced by what has been found in previous cases. To allow new themes to emerge, it is crucial to thoroughly and systematically follow the steps outlined by IPA for each case (Smith, Larking, & Flowers, 2009). Thus, individual cases were considered on their own terms, allowing new themes to emerge from each case. After conducting the analysis for each case, cross-case patterns were established and documented in a table of

themes for the group. This information was transformed into a narrative account supported by verbatim extracts from the participants. An experienced IPA researcher reviewed and audited the analytic journey to ensure firm grounding in the transcripts.

During the latter stages of analysis, negative cases were investigated, using cognitive behavioural functional analysis (CBT/FA). CBT/FA is compatible with IPA in that it is an idiographic assessment, concerned with understanding individuals' characteristics, and can help to identify specific cognitions, emotions, and behaviours, and any subsequent interactions. CBT/FA can be a useful device to help overcome the categorical limitations of IPA classification by accommodating a more dimensional, process level analysis. The Andersen model (Chapter 1; Section: 1.2), was used in the final drafting of this thesis. This model provided an additional framework to systematically categorise the complex and wide-ranging topics presented in the literature review. It was also helpful to triangulate findings from the present study and to assure that research questions were addressed at all levels (Chapter 8: Section: 8.3.3).

## **2.9 Ethical Issues**

Central to the approach used in this thesis, was a strong commitment to the development and maintenance of professional ethics, skills, and conduct (BPS, 2009, HCPC, 2012). Every effort was made to work responsibly, and with integrity, ensuring that participants' rights, safety, and wellbeing were central to the research process. Several ethical issues were identified and presented below.

- i. Maintain anonymity of all participants, given they were recruited from small towns and villages throughout the three district councils in Ayrshire (North, South & East); protecting participants rights to confidentiality (HCPC, Section 9, pp. 11; BPS, 2009, Section: IV, 1.3, pp. 12).



- ii. Another concern was that the research team acknowledged and familiarised themselves with culturally sensitive issues throughout the research process (e.g., culturally held health beliefs); thereby demonstrating respect, and positive regard for participants (BPS, 2009; Section: IV; 1.1, pp. 10)
- iii. Ensured that translators were available for individuals who were not proficient in speaking or reading English so that they could make informed consent and understand they might not personally benefit from this study, and understand their rights as participants (e.g. withdraw from the study at any time).
- iv. Ensure that translators were available for individuals who were not proficient in speaking or reading English so that their experiences and perspectives were accurately captured; thereby demonstrating respect, and positive regard for participants (BPS, 2009; Section: IV; 1.1. pp, 10).
- v. Participants' need and right to information about the study (HCPC, Section 9, pp. 11; BPS, 2009; Section: IV, 1.3, pp. 12)
- vi. Informed written consent that could be easily translated (HCPC, Section 9, pp. 11; BPS, 2009; Section: IV, 1.3, pp. 12)

After identifying ethical issues associated with this study, the following measures were considered appropriate:

- i. Development of a Participant Information Sheet (Appendix: 4)
- ii. Development of a consent form (Appendix: 5)
- iii. Every attempt was made to maintain participants' anonymity (e.g. to change participants' name, and the name of town or village of residence). Only the minimal amount of demographic information was captured.
- iv. The researcher familiarised herself with the literature on cultural sensitivity, religious

and cultural norms and beliefs of various ethnic minority groups; and referred field notes and reflections from the Scoping Project to inform the approaches used in this project.

### **2.9.1 Interpreters**

Guided by the literature reporting the challenges of a lack of English proficiency (LEP) among BME groups (DeCamp, et al., 2015), it was determined that interpreters should be recruited to manage possible language barriers. The scoping project (Preface; Chapter 1. Sections: 1.1; 1.3.1.3), was important when arranging translators, who were contacted regarding the possibility of utilising their services (e.g. Cantonese, Polish and Punjabi). After several discussions with key community members (Chapter 2: Section: 2.4.2), it became apparent that interpreters were only required for participants from the Chinese community (Language: Cantonese). The interpreters were coached on the interview methods used (Section: 2.7/1), and every effort was made to ensure that the lines of questioning would be easily translatable and understood (Section: 2.9/v; Appendix: 3). The interpreters had vast experience of working with elders within the Chinese community and were proficient in speaking Cantonese. Interpreter A assisted with the interviews with the sample of women from the Chinese community which facilitated rapport with participants and enabled a smooth transition from introductions to the women feeling confident to communicate in English for most of the interview. The interpreter was also helpful in translating terms that the participants struggled with. Interpreter B's skills were also required for the interviews with a sample of men from the Chinese community, to facilitate the introduction of the study, to answer questions about how the interview would proceed, and how the data would be used. An important role for interpreter A and B was to ensure that participants' questions were answered and informed written consent was sought (Appendix: 4 & 5). Thereafter, participants decided they would speak directly to the researcher in English, with limited assistance and input from the translators.

## Chapter 3

### Results

Data analysis followed the guidelines provided in the IPA literature (Smith & Eatough, 2007; Smith & Osborn, 2008). This approach is inductive, allowing ideas and themes to emerge from the personal accounts rather than imposing a predetermined theory. This study intended to gain insights into the perspectives of the study's participants' experiences of accessing health care services in Ayrshire. Analysis not only achieved the main objective of this study (Chapter 1: Section: 1.7.1); but established both descriptive and analytic categories based upon the identification of associations of '*similarity and difference*' (Dey, 1999), within and across participants' accounts. Through a process of identifying, refining, and integrating categories, the analysis found a complex interaction between cognitions, emotions, and health behaviours, which were meaningfully understood by participants. IPA is not concerned with generalisation, and it is, therefore, important to emphasise at this juncture that the results here presented, cannot be used to generalise to others (individuals or groups of BME communities), beyond the scope of the present study. The results are presented in four chapters (Chapter 3 to Chapter 6), which offers an in-depth analysis of participants' accounts. The analysis is illustrated through the use of four super-ordinate themes: 'It's a Trust Thing' (Chapter 3); 'Minding the Gap(s)' (Chapter 4); 'Sexual Health: a Culture of Silence' (Chapter 5); and 'Personal Perception of Risk' (Chapter 6).

### 3 It's a Trust Thing

One recurrent theme of the narratives was a diminished sense of trust in primary care services, and for some, a distrust of the NHS, which seems to have been the resultant effect of a series of beliefs, underpinned by negatively held attitudes and expectations of care. The resultant effect was that some participants returned to their homeland to receive treatment from a health system they trusted.

### 3.1 Trust in Physicians in Differing Health Care Systems

The majority of participants expressed a high level of trust in physicians and in the health care system of their country of origin. Despite some participants leaving their country of origin over thirty years ago, high levels of interpersonal and organisational trusting relationships remain. The most commonly cited reasons for high levels of trust were captured in Kate's narrative, she said:

*I would say our doctors are better educated than doctors over her....they know how to solve problems and understand how to think laterally about health issues. So even when they come across unusual problems, they know how to deal with that, they can give you information about that subject.*

Kate (Polish)

The analysis found that Chinese participants have a particularly high level of trust in the medical approach used in Hong Kong (the homeland of the Chinese community in Ayrshire). Analysis established that traditional Chinese medicine (TCM) is used as an alternative, and as a complement to Western medicine, as it is believed to have specific healing properties. TCM is believed to work on a holistic level, in as much as it creates “*balance* in the body’s “*energies*”, and can be used to “*treat the whole body*”. This finding suggests that participants trust both types of medical approaches used in Hong Kong, and take account of the strengths and weaknesses of both when deciding how to treat symptoms experienced. This finding upholds a study conducted by Lam (2001), who reported that Hong Kong Chinese participants perceive TCM and Western medicine to have very specific strengths and weaknesses. Another source of trust found in participants’ accounts was associated with the positive experience of accessing efficient diagnostic services and being cared for by

clinicians who were considered to be responsive and effective in the management and treatment of symptom experienced. Peter explains.

*...we go back to Hong Kong, get tests one day, results the next and then get powerful medicine that works. That doesn't happen here. I got x-ray two months ago, no results, so I'm going back to Hong Kong for tests; they find the problem, know what to do.*

(Peter, Chinese)

James' narratives reflect Peter's experience of using health care in Scotland, and how it differs to the approach used in Hong Kong, which offers insight into why he and many people within his community return home (Hong Kong) to receive medical care. James says:

*Medication between here and Hong Kong is different. In Hong Kong medicines much more powerful and give people comfort. They use injections to stop disease spread out, here they give you tablets, too slow, not help them. They say, go home, drink plenty, eat fruit, plenty rest, plenty drink. In Hong Kong, they give you a jab and give you more medication and it works.*

(James, Chinese)

The apparent potency of Western medications prescribed in Hong Kong and the mode of administration work to reassure patients, builds confidence and trust that symptoms are being controlled and treatments are effective. Participants' high level of trust in physicians and health care systems of their respective country of origin were associated with a greater willingness to return to their homeland for medical care. This finding has resonance with previous research reporting that trust in physicians and trust in the medical profession are

important in terms of establishing and maintaining successful therapeutic relationships (Hall, Dungan, Zheng, & Mishra, 2001), and are associated with more willingness to seek care (Greenfield et al., 1988). Critically, it is also important to note that trust and trustworthiness have previously been reported to increase with ongoing exposure, as individuals understand the needs of others over time, and are more able to adapt to each other's preferences (Axelrod, 1984). This may account in part for the high level of trust in physicians and health care systems in their respective countries of origin.

### 3.2 A Diminished Sense of Trust in Primary Care Services

A diminished sense of trust in primary care services was commonly based on a single consultation with a general practitioner (GP). GPs interpersonal skills, information-giving skills and clinical competency were called into question and led to a diminished sense of trust. Participants described that their level of trust in the NHS was influenced by much stronger forces such as low expectations of care, values and negative attitudes about the NHS before leaving their homeland. To illustrate Kate said.

*Well, the problem is finding a doctor who will listen to you, and who knows how to solve the problem, know exactly what it is. So here....they don't know anything, can't give you information and have to look up a book to get you medication. They don't listen, don't spend time with you and can't answer any questions....we were told this before we left Poland....so we have no confidence in GPs, it is better for us to just go back home when we're ill and need to see a doctor. So that's what we do, we go back home for our medical and dental care.*

(Kate, Polish)

A diminished sense of trust was strengthened for participants who had concerns about the way in which their GP related to them, with reports of not feeling listened to, and a sense that their health care needs were fully not understood. Trust was further compromised by concerns about their GPs' level of competence and clinical judgment. Participants who experienced difficulties articulating their health care needs recalled feeling that their "...knowledge and experience" was undermined by their GP. For other participants, a diminished sense of trust was articulated as having "no confidence", in primary care physicians, which led them to feel dissatisfied, and reluctant to seek care in Ayrshire. The resultant effect was typified in Kenneth's narratives (Indian gentleman, age: 65; living with multiple comorbidities), who reported feeling "dehumanised", "depressed", "angry", and "unhappy with care".

### 3.3 Distrust of the National Health Service

A high level of distrust in the National Health Service (NHS) was found across all participants' accounts, with the strength of feeling being stronger in the narratives of David (Black African). Distrust for this man was expressed as uncertainty, and doubt about how confidentiality was managed within the NHS, and as a concern for his personal autonomy; which resulted in a reluctance to use health care services. A distrust of the health care system and an unwillingness to use health care provision relates to normative practices in the country of origin, and a vulnerability associated with chronic illness (e.g. HIV). Within participants' narratives were concerns about the intentions of the health care professionals. To understand this finding more fully it is important to situate it within the context of individual experiences and culturally defined expectations. David explains:

*Back home we speak to a medical practitioner, that information is not private and confidential; it is in the public domain...we don't know if it will be kept within the health services. No confidence, even people working in hospitals, they can take information*

*outside, so for that reason, people tend to have no confidence, they tend to be reluctant to go to hospital because there is no anonymity.*

(David, Black African)

The antecedents to participants' distrust (particularly for David: Black African) seemed to arise from normative practices in their countries of origin, rather than through personal experience of using the NHS. In addition, there appears to be a common perception that "*doctors undermine the knowledge and experience*" of this particular BME population; this has impacted on some participants' psychological well-being. Kenneth, an Indian gentleman (age 65), who has a range of complex health problems, reports feeling "*dehumanised*", "*depressed*", "*angry*", and "*dissatisfied with care*".

The day to day management of chronic illness for many people is problematic, but in this vulnerable BME population, it is intensified by the belief that their culturally valued held beliefs and experiences are challenged by health care providers. These results indicate that there is a reluctance to use needed health care services; thus raising serious concerns for preventative screening, maintenance of chronic health problems, and compliance to medical regimens.

### **3.4 Distrust of Western Medicine**

Beliefs about the potency of Western medicine prescribed in the West, culturally defined philosophical understandings of health and wellbeing, and dissatisfaction with care was found to further diminish trust and to reduce the likelihood of participants utilising health services across Ayrshire in the future. Capturing the essence of her fellow participants' views of the NHS experience, Susan explains.



*I've had this pain problem, so I go to the GP, and he says I'm fine, go home, have paracetamol. Every time we are meeting together I would say to the GP, I'm depressed, exhausted because of the pain; but after four week, still sore...so last time went to GP, I worry because the painkiller doesn't work... Then I get another kind of treatment, still doesn't work. Then I went to Chinese doctor and got therapies to get the pills to work and it got better.*

(Susan, Chinese)

Within Susan's narratives were concerns about Western medicine and the potential threat it poses to the body, and by failing to adopt a holistic approach to health. Susan continues:

*So I believe Chinese medicine may be the best for balancing energies, treats the whole body, Western medicine, you have a head problem, it's your head, you get a stomach problem, it is just your stomach, they don't see it may all be related. Western medicine is different from our medicine, different from traditional and contemporary Chinese medicine. So we have no trust in Western medicine or medical practices. Don't trust Western medicine; think it is a threat to other bodily systems.*

(Susan, Chinese)

The belief that Western medicine is ineffective in both diagnosis and treatment is strengthened by personal experiences, serving as a testament and reaffirms health beliefs, to explain, Peter, said:

*My sister, she had pain in her arm, shoulder and right side, she was like that for months. She kept going to GP, they give her basic medicine see if it works, try a slightly better one next week,*

*and if that doesn't work try a better one again, and if that doesn't work, okay get the best one. They give you inferior one first. So we sent her to Hong Kong for tests, she got MRI scan, X-rays, blood tests one day, results the next day, she had liver cancer and died in Hong Kong, it was too late. So you're reluctant to go to GP, I have no confidence. I'm going back to Hong Kong, they find the problem, know what to do.*

(Peter, Chinese)

Peter's narrative reflects the views of many participants who spoke about the strength or quality of medicine prescribed by GPs, a delay in receiving a timely diagnosis, the lack of readily available technologically advanced diagnostic tests and subsequently his lack of confidence in the system; thus fuelling the decision to return to Hong Kong for medical attention within a health care system they know and trust.

The medical approach used in Western medicine in Scotland was commonly regarded as ineffectual. The participants shared concerns about the approach to health care were felt by all ethnic groups who offered an explanation of why they do not make full use of the NHS. Kate's words clearly capture their sentiments, she states:

*The health services here are very poor we feel. I had to tell the GP what he should give me, as he did not know. So I was telling him rather than him telling me. So GP are not good here. We have no trust, no confidence in NHS*

(Kate, Polish)

It is important to reiterate that the participants from the Chinese community who took part in this study go to great efforts every year to return to their homeland to access and engage

with a health care system they know and trust, to meet their health care needs. To illustrate, Peter (Chinese), explained that he “...saves thousands pounds all year to return to Hong Kong to get health checked. You see the doctor, you get scan, you get powerful medicine, and traditional Chinese medicine...all in one day...that’s it”.

### 3.5 Diminished sense of Trust and Differential Communication Styles?

There was a salient lack of dialogue within participants’ narratives about instances of shared decision making and discussions about preferred treatment options. This finding suggests that the experience of a diminished sense of trust may be related to differential communication styles. It is argued that the majority of participants may use a more passive engagement style within the clinical interview. It is outwith the scope of this study to assert whether or not the aforementioned GPs made attempts to defer to their patients’ engagement style, and preferences or the extent to which any attempt made was effective (Edwards & Elwyn, 2006). Nevertheless, the interpersonal tensions outlined above were another source of concern that further compromised participants’ trust in primary care services.

### 3.6 Negative Case Analysis 1

A negative case analysis was conducted to ascertain the validity of the analysis, and to inquire more fully about how participants’ made sense of trust. Negative case analysis is an important analytic device used to explore more fully qualitative data that seem to be “set apart from the other data collected”, and to confirm reliability, and accuracy of earlier analysis (Denzin & Lincoln, 2005; Taylor & Bogdan, 1998). Conducting a negative case analysis was particularly important for the present study, as 1. Participants were not a homogeneous group; 2. There was a high level of convergence and divergence within, and across participants’ accounts.

This level of analysis confirmed earlier findings outlined above and made it possible to identify biased cognitions within and across participants' accounts. These findings explain more fully the process by which a diminished sense of trust and distrust of primary care services was extended to the NHS and wider health development; despite participants having only minimal contact with primary care services, and no or limited contact with secondary care services.

Using cognitive behavioural functional analysis (CBT/FA), it became clear that participants were categorical in their thinking style (good vs. bad), and their decision not to trust was the resultant effect of focusing mostly on one consultation. Despite limited exposure, there was a tendency to express a dislike and a distrust of primary care services. This finding differentiates trust as being conceptually different from a dissatisfaction with care; and can be understood by the 'mere exposure effect', which asserts that people have a tendency to quickly form judgments and to "*unduly dislike things*", simply because of a familiarity or unfamiliarity with them (Bornstein, 1989; Zajonc, 2001). Critics argue that the benefits of making rapid decisions (e.g. minimal energy and time required), can introduce the risk of bias (Shah & Oppenheimer, 2008), which can lead to cognitive errors, and erroneous judgements (Beck, 2015). The present findings add to this body of work by establishing how this group of participants used minimal effort, and limited evidence to make decisions, which led to a diminished sense of trust in primary care services.

Applying a cognitive behaviour approach (CBT) shed light on the process by which a diminished sense of trust and distrust from primary care services was extended to the NHS and wider health development; despite participants having minimal contact with primary care services, and no or limited contact with secondary care services. It became evident that participants used generalisations (cognitive error), which served as a device to reinforce existing negative thoughts, and led participants to draw a generalised conclusion (e.g. if a

negative experience can happen once, it can happen again). This biased cognition influenced participants' health behaviour through avoidance of the same types of places or situations associated with the original stimulus that remind them of the negative experience. It is proposed therefore that trust in the health care approach of physicians was generalised to trust of the wider health care system in participants' country of origin. A diminished sense of trust in primary care services in Ayrshire was generalised to participants having a diminished sense of trust in the NHS. Similarly, distrust of a geographically distant, and structurally different health care system was generalised to a distrust of the NHS and the wider health development.

The analysis confirmed trust can be situated within rational thought processes, which demands evidence of conscious awareness of expected costs and benefits (Axelrod, 1984). This was evidenced by identifying ways in which participants' conducted a cost-benefits analysis. There was compelling evidence within and across participants' accounts of active comparisons being made between facets of the health care systems of participants' respective countries of origin to the NHS in Ayrshire; this was achieved by weighing up the pros and cons when they decided not to trust.

This level of analysis not only upholds earlier analysis, but deepens our understanding of trust as being bound in participants' moral judgements (e.g. health attitudes, health beliefs, values, and norms), and rational thought processes. It is from these two fundamental processes from which expectations were formed, and decisions were made about whether to trust or not. In addition, it is argued, that it is from these two processes that decisions were made about participants' willingness to engage with particular physicians and health care systems. This evidence suggests that the varying dimensions of participants' trust can be conceptualised within a heuristic model (Chapter: 7; Section: 7.1.5/1).

## Chapter 4

### 4 Mind the Gaps

Enveloped within participants' narratives were clues to serious health disparities that were echoed in terms of gaps in knowledge and understanding about the NHS, and varying gaps in community members' ability to communicate their health care needs. Considerable gaps in knowledge about local health services, uncertainty about how to navigating needed services and health-related information were found. Participants' values informed decisions about when to access care (e.g. only when it is absolutely necessary, or as '*a last resort*'), and screening programmes were considered a '*waste of GPs time...*' Health communication problems were widely reported. Varying levels of ability to understand health information and articulate needs were underpinned by major gaps in the ability to communicate in the written or spoken form. Problems with illiteracy, LEP, and a lack of professional interpreter compromised the clinical interview and increased the risk for misunderstanding, missed diagnosis, poorer health outcomes, and unmet health care needs. The following analysis offers insights into some of the causative factors that situate Ayrshire's BME groups at high risk of experiencing inequalities in health.

#### 4.1 Gaps in Knowledge about General Health Care Services

The health care system in Scotland is characterised by universal access. Despite this, there was strong evidence of a gap in participants' knowledge about available health services, lack of awareness of screening programmes, lack of understanding of how the health care system works, unfamiliarity in terms of navigating needed services and health-related information; these were considered to be among the major barriers to needed care.

Joseph's narratives capture the shared feelings of his fellow participants. He explains:

*...we don't understand the system in this country, how it is monitored, who to approach, what to do. To our experience, we have been here for more than 27 years; you are the first person who has approached us. So to talk about this, as we will do now, nobody has ever done that. So who do you approach? What do you say? When do you approach? In what circumstances?*

(Joseph, Indian, Sikh)

There was a sense of realisation in Joseph's narrative that after almost three decades of living in Scotland, he remains unaware of available health care services. Joseph's questions clearly demonstrate gaps in his knowledge about how to navigate the system and difficulties in articulating needs.

#### **4.2 Gaps in Knowledge about Sexual Health Screening Services**

The lack of understanding and awareness about how to navigate services prompted a question enquiring about knowledge of general and sexual health screening programmes available in Ayrshire. Margaret's narrative reflects a shared response by her fellow participants. Margaret said:

*Sorry, sorry, what is that? I don't know anything about it. Don't forget doctors don't send that information here, the GP doesn't do that. Well, at least we haven't seen it. No, no, no I never heard of these things. What are screening services?*

(Margaret, Thai)

Unaware of the availability of sexual health screening programmes and the purposed aims of the services underscores the extent of the gap in knowledge within this sample of people.

An extract from Lucy's account reiterates the extent of the problem. Lucy explained:

*Well I know there are smear tests available, but that's the only thing that I know. I don't know of anything else. As for other Asian ladies they all know about smear tests that you wait until you get a note from the doctor, but we don't, I wouldn't know where to go or who to ask about any other screening service. Could I go to the doctor, or maybe the nurse, something like that, is it?*

(Lucy, Chinese)

Both Margaret and Lucy's narratives indicate that general and sexual health screening services are either invisible or non-existent. However it is only part of the picture; participants' accounts offered other rationales explaining why screening programmes are not fully utilised by Ayrshire BME population, Martha explains.

*I don't know, cause I would think that if you're not really ill, you were time wasting, and I think that's the worst thing that you could do to them, waste a doctors time. See we all think, I think, that you're going for a check-up, you don't do that, it would need to be pretty bad before we would go to the doctor.*

(Martha, Indian, Sikh)

It seems that cultural driven values exert an influence on participants' decisions about the appropriateness of accessing GP services, and to determine that this ought to be done only when it is absolutely necessary, or as "a last resort". Preventative health strategies are regarded by several participants to be enveloped within a holistic philosophy, which does not



usually involve actively seeking out medically based preventative health screening programmes; this concept seemed by many to be a “*waste of GPs time...when there is nothing wrong with you.*”

The findings offer strong evidence to suggest that significant gaps in participants’ knowledge about available health services, and health promotion material impact on the uptake of health care services and health promotion resources. Against these difficulties were gaps in understanding about how to approach key service providers, and, there were varying gaps in the ability to articulate need. Considerable gaps in awareness of preventative screening programmes and understanding of how to navigate the health care system were commonly reported. Challenges preventing the re-uptake of services were cited as “*long waiting times to see the GP, and even longer waiting times to see a specialist or get results from medical tests*”

#### **4.3 Gaps in the ability to Communicate Health Care Needs**

Participants explained that they experience a significant gap in their ability to communicate their health care needs, source health information and support due to problems of illiteracy. The extent to which participants experience problems communicating their health care needs, accessing health information and negotiating quality care is exemplified in Peter’s narrative.

He explains:

*The main problem we have is the issue of communication. Our elders have problems accessing help, accessing information, language barrier and little translation material, and there is a problem with literacy. So there are problems, and there is no understanding as there are difficulties in reading. Others can read, but don’t understand the words. And the medical, we don’t*

*understand most of the words, many we have never heard before.*

(Peter, Chinese)

Peter identified a number of problems stemming from poor communication. For example, he showed that the lack of ability to read and write prevents many from taking action to seek out needed medical help and precludes many from accessing health information because they cannot understand many of the terms and phrases used in health promotion material. Understanding the effects and difficulties that arise from having limited or no reading skills, prompted Joseph to voice his concerns on behalf of his peers. He said:

*All my circle is around 50 so at that age, we do start picking up health problems. But we don't know what we might have or don't have. The main difficulty is language barriers, lack of language cause gap in our knowledge, difficulties in accessing health service and accessing information. If the language is not there, knowledge is not there, communication is not there, so nothing gets sorted.*

(Joseph, Indian, Sikh)

Within Joseph's narrative was a palpable sense of an increased awareness of a vulnerability to ill health with advancing age, compounded by a sense of lack of agency to seeking out information, and to articulating health concerns, thus reducing older participants' sense of autonomy and decision-making powers.

#### **4.4 Communication Skills Gaps: Lack of English Proficiency (LEP)**

Within a primary care context, the clinical interview was compromised for a number of participants who relied on the help of a friend or relative and in some cases a child to act as

an interpreter. Having friends or close family present to interpret was considered as being 'essential' to facilitate the communication process. Conversely, the presence of a significant other was also regarded as an 'invasion of privacy', which served as a barrier to communication in as much as participants felt unable to speak 'freely and openly' with their physician.

In an attempt to bridge the communication gap and facilitate access to health care, a few key individuals from various BME groups volunteer to act as translators for elderly members of the community which is particularly problematic as they themselves have only limited English. The potential for misunderstandings during a clinical consultation was considered very high as the translators' experience "great difficulty" deciphering and translating "technical medical terms". Kenneth explained, "the message from the doctor or the patient aren't understanding much, it's frustrating... the doctor can't look properly after the patient because the communication is not right." Kenneth continues:

*See my wife is taking some of our people to hospital, and she can't speak English, or speaks broken English, but she is going to interpret for them... and struggles to understand.*

(Kenneth, Indian, Sikh)

There is a clear understanding of the restrictions and risks involved in not being able to accurately interpret complex medical information; efforts exacerbated further when one's own mastery of English is limited. Kenneth outlines his anxiety below:

*There are certain words in English she doesn't know to translate them into our language and the same, to translate them into English. It's the same if they get medication, you can't read the*

*instructions, what dose you've to take or what times and how many times a day you've take medicine. And the problem gets worse if you've got more than one type of medicine, or it reacts with your body, we don't know how to explain that, and when doctor gives special instructions don't know what he means or what diagnosis is. It's a big problem maybe giving wrong information to people, and it's a language barrier.*

(Kenneth, Indian Sikh)

The lack of English language makes the health care experience fraught with difficulties for these participants. This has major implications for shared understandings and decision making between the doctor and patient, adherence to prescribed medication and for health outcomes.

Lina, like many of her fellow participants, is bound by a heavy workload and fixed time constraints; her narrative offers an insight into difficulties that arise when assisting her elderly mother (who has no English) to regular GP appointments. Lina explains:

*See language is the biggest barrier. When you have to go to the doctor with my mother, either I or she has to go by herself or she has to take one of the children with her. There is no way around it, or I write notes and say this is what's wrong with her, please give her something. But it is not the same communication as it would be if you were there face to face. You see when they get a response back, they don't know what they are saying, and not every doctor has time to write a note to say this is what the problem is.*

(Lina, Indian Sikh)

The reliance on sending notes to a GP, or calling on the assistance of children to mediate and explain complex medical symptoms (experienced by another) was understood as being problematic for the patient, the doctor and the child involved. It was understood that this could seriously compromise the clinical interview by limiting disclosure of potentially important health information, such as perceived severity and duration of symptoms.

Lina continues:

*You see that's a big problem, who wants to take a child to the doctors when you have something embarrassing wrong with you or a private matter. Like down below, or your breasts or something like that. Then the guys won't take the children with them if they have a guy's problem. How could a child explain something like that? You feel embarrassed yourself; feel humiliated yourself without turning around and saying what is wrong with me through a child. So you've got your privacy bits there that comes into it as well...your privacy is invaded by someone being there when it should just be yourself and the doctor so that you can speak freely to them.*

(Lina, Indian Sikh)

All participants from the Chinese and Indian communities openly talked about having significant gaps in their ability to read and write. These same two groups of participants report a very low uptake of health care services. A lack of English proficiency (LEP) was particularly evident in the narratives of men from the Chinese community, and both men and women from the Indian community who took part in this study. Participants' from these

groups are at a distinct disadvantage, as they fail to understand information, misinterpret instruction and cannot readily convey their concerns or symptoms experienced; which compromising the clinical interview. As such, participants' reported feeling "*depressed*" about the current problems and "*anxious*" about causing offence to service providers if they attempted to raise their concerns. A LEP was reported to act as an insurmountable barrier to preventing this group of participants from forging better relationships with their GP, articulating needs, and from making use of informational, decisional and interpersonal support.

#### **4.5 Gaps in Ability: Communicating Symptoms & Concerns**

The problems are not limited to a lack of literacy and a LEP. Participants have problems communicating their symptoms, due often to difficulties in interpreting culturally defined health beliefs, and ways in which they make sense of symptoms experienced. For example, Lee explained that the Chinese way of describing "*emotional or psychological problems*" would involve situating them in terms such as "*hot and cold within the body*", which he finds difficult to translate, and understands that this interpretation poses problems for Western physicians to make an accurate diagnosis. He says, "*...sometimes there is no English word*".

## Chapter 5

### 5 Sexual Health: A Culture of Silence

Analysis showed how silence towards the topic of sexual health was meaningfully understood and managed by participants. In addition, there was strong evidence to argue for an intentional use of silence and to show that silence in a sexual health context has important functions, as well as salient and pervasive effects.

#### 5.1 Silence: Participants' Characteristics

Within participants' narratives was a prevailing sense of discomfort and unease about the topic of sexual health. Strong emotional tones of anxiety and fear that fosters silence were detected in the analysis. Participants explained that *"sex is a private concern"* and many felt embarrassed about the prospect of discussing it; stating that even married couples *"do not talk to each other about sexual matters...see we didn't get sex education at school..."* All participants, with the exemption of one (Indian, male) found the *"topic"* of sexual health caused them to feel embarrassed and to experience a sense of *"shame"*. Participants reported a number of other factors that inhibited their ability to openly discuss sexual health concerns. The most commonly reported difficulty was having *"insufficient knowledge about sexual function"*, and *"dysfunction"*, *"discomfort with sexual language"*, *"lack of information"* and an apprehension that any sexual health enquiry may cause *"offence"* to others. The *"fear of being embarrassed"* or *"causing embarrassment"* to others were commonly reported. Participants' negative attitudes towards the topic of sexual health seemed to arise from *strongly felt* values, and from endorsed culturally defined arbitrary rules (*"...we can't talk about sexual matters"*).

## 5.2 Silence: Values and Beliefs

Marked differences in participants' level of discomfort, and willingness to engage in discussion about sexual health were apparent. Among the study's participants', it was these two Chinese men (age: 54 and 59), and the Polish woman (age: 27), who seemed to be the most reticent about engaging in discussions about their sexual health experience. Despite alluding to possible sexual health problems, these Chinese men were the most resistant to openly discuss their concerns and appeared to be very uncomfortable when the topic was introduced. Conversely, Indian participants (men and women) seemed to be the most comfortable and were the most willing of all the participants to talk about their experience of seeking help for sexual health concerns.

The salience of silence about sexual health found in the accounts of these Chinese men and Polish women were expressed as values and beliefs, central to which were concerns about their moral character and personal identity. Within these Chinese men's narratives was a strong sense of core values which served to impose upon this group of men's capacity to engage in discussion about possible sexual concerns. Peter offers an explanation:

*We don't discuss sex; we can't talk about sexual matters. Just we don't do it, not even among ourselves. Even if something's wrong, we just put up with it, we don't tell anyone, it's shameful. You see we don't talk about our personal problem, that's the main thing, fear to get embarrassed, or embarrass other people you know. We're scared, shy, embarrassed to talk about sexual health. Even talking about water works, anything to do with that area, just don't mention it. You got problem there, just ignore it. Any topic around private part, can't talk about it.*

(Peter, Chinese)



Finding the topic of sexual health objectionable was central to core values and beliefs that disclosure about one's "*private life*" would carry connotations about one's personal character. Within participants' accounts were indications to suggest that silence has a protective role in the context of sexual health. As Kate explains:

*You talk about sexual health they think you are leading a dangerous life...we are quite traditional and conservative about sexual health matters. We usually come to UK as couples, and only really date within our own community, so we are quite traditional and conservative about sexual health matters.*

(Kate, Polish)

The strength of association between the prospect of discussing sexual health issues and participants' values were influenced by anxieties about being negatively judged by others. David's (Black African) concerns influenced his decision "*not to openly discuss sexual health*" citing feeling "*very frightened*" that the people may think he may have a "*sexual disease*".

### 5.3 A Pervasive Culture of Silence

All participants talked about how their physicians had never enquired about their sexual history and acknowledged the role of their own personal lack of knowledge of sexual dysfunction and disease had in preventing them from asking questions or making an enquiry during a consultation with their GP. Martha Says:

*My doctor never asks me anything about private parts or if I'm okay in that department, and I don't know what to say when I've*

*got problems there, so I don't know if it's normal or not normal, so I just leave it. I'm worried about the menopause, but I don't know if I've got the menopause or something else is wrong, I don't know what to ask.*

(Martha, Indian, Sikh)

At the time of the interview, only one participant (Indian man) discussed his experience of actively seeking medical help for problems of sexual dysfunction. Kenneth explained his history of *"impotence" which he believed to be* a direct effect of his diabetes (Type II), and argued that his general practitioner (GP) was *"reluctant"* to prescribe medication that his *"specialist recommended"*. This decision, Kenneth believes was based entirely on *"the GPs budget"*, causing him to feel that his sexual health *"needs"* were not fully understood, as such, he had to continue to live a *"restricted life"*. Within Kenneth's narratives was a palpable sense of the unimportance of sexual dysfunction within primary care services, and a lack of care for the impact it has had on the quality of his life. Kenneth was not aware of any attempts by his GP to engage him in shared decisions about alternative therapies, and he does not recall being offered information that may have helped to better manage his condition. Best practice calls for a person-centred model of care (Epstein, et al., 2005), which takes account of patients' preferences (Bruera, Willey, Palmer, & Rosales, 2002), and attempts by health care professionals to engage patients in shared decision making (Galloway, 2013). It seems that Kenneth was denied these rights, due to tensions around discussing and treating sexual health problems within his primary care service, which needs to be understood and resolved by further research.

The culture of silence about sexual health within primary care services across Ayrshire and Arran Health Board seems to be a pervasive issue. All participants unanimously report that their doctors *"never"* enquired about their sexual history, or talked to them about potential

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sexual health problems or concerns. Among their working practice seems to be a type of silence that prohibits physicians working in primary care from routinely enquiring about this group of BME community members' sexual health concerns. The implications of not eliciting concerns resulted in this group of people believing that their physicians are "*reluctant*", "*disinterested*" or "*unskilled*" in sexual health management.

## Chapter 6

### 6 Personal Perception of Risk

The analysis offered insights into the ways in which participants made sense of and responded to their personal perception of risk. Across participants' accounts were differing conceptions of risk, which informed health decisions and reflected complex cognitions, comprising of strongly entrenched health beliefs, attitudes, and emotions. There was strong evidence to argue that participants' understanding of their personal perception of risk can be conceptualised within a heuristic model (Chapter: 6 Section: 6.8; Chapter 7: Section: 7.4.3). This chapter presents differing conceptions of risk (i.e. Risk of Stigma', Risk of Heart Disease and Diabetes', Risk of Breast Cancer and Cervical Cancer', 'Risk of Nasopharyngeal Cancer and Liver Cancer'), as understood by participants.

#### 6.1 Risk of Stigma

Chinese and Black African men's personal perception of risk was similar in terms of a vulnerability to stigma (Chapter 6: Section: 6.6, 6.7). Stigma was understood by the men as a mark of social shame, which could bring reproach on their personal character and reputation. These Chinese men's perception of risk differed from the risk perceptions of David (Black African), in terms of their vulnerability to illness stigma (Chapter 6: Sections: 6.2). In contrast, David's personal perception of risk was understood as a vulnerable to HIV-related stigma (Chapter 6: Section: 6.5). Analysis showed that for the present participants, a vulnerability to stigma acts as a barrier to help-seeking behaviour and to accessing health care services, which put them at risk of poor health outcomes, and at high risk of experiencing health inequalities.

## 6.2 Illness Stigma

These Chinese men's perceptions of ill health were contextualised within historic social and cultural norms, embedded within which were negative connotations about ill health. Peter explains:

*It's cultural, he's got a disease, people don't want to come close to him in case he pass it onto me. So it's the knowledge of the health, the disease is a threat. Still today we feel this, you have a disease, they don't come close to you....so you just don't tell anyone, just keep it to yourself.*

(Peter, Chinese)

These powerful narratives indicate that those who are perceived as being ill or carrying a "disease" may face real or imagined threat to their social relationships. These Chinese men have concerns about posing a risk to the immediate community and are fearful about the prospect of being rejected by family, friends, and the Chinese community if it were known that they may suffer from poor health.

James' narrative illustrates other culturally held normative beliefs and behaviour that maintain these Chinese men's personal and social identity. This is evidenced by these Chinese men's reluctance to discuss their personal health problems and prohibits them from engaging in help-seeking behaviour. As James says:

*Man doesn't want to talk open because to save face, keep dignified they think they can solve problem. They talk themselves, I can manage, I can manage...not good for anyone to think man's not coping with problem, or have health problem. We need to keep strong, let them see we are strong.*

(James, Chinese)

These thoughts and subsequent behaviour help to maintain this group of men's sense of vulnerability to experiencing a risk of illness stigma, and public-perceived stigma. The culturally driven need to maintain a sense of normality, dignity and pride supersedes any immediate concerns these Chinese men have about their health. The threat to personal identity is compounded by a traditionally held "*fear of losing face*" and concerns about "*bringing shame*" to family members and the wider community. In an attempt to protect family and friends from the burden of the individual's health problem, these Chinese men "*do not speak about health problem*". Peter explains:

*Traditionally, a problem in the family, don't talk about it to anyone, outside or the whole community will know about it. Don't want anyone to know if they have a personal problem. Fear that people will talk about them, that's the fear of losing face. Even if they have problems about health, won't even tell family. One person's worry is better than whole family worrying. Even when we got a disease; they don't want people to know about it.*

(Peter, Chinese)

The analysis suggests that illness stigma was understood by these men to be a reflection of their own culturally defined stigmatising attitudes towards the manifestation of physical, emotional or mental disorders. This finding adds to the stigma literature as these Chinese men's perceptions of risk of illness stigma have no boundaries in as much as any sign of ill health, manifesting as a disease, dysfunction or impairment are stigmatised. This finding differs from reports presented in the stigma literature, which suggests that mental disorders carry more stigma (and subsequent discrimination) than other illness within the general population (Sartorius, 2007).

The present study also differs from the notion that there are specific diseases that are stigmatised more than others (e.g. mental disorders, AIDS, venereal diseases, leprosy, and certain skin disorders), within the health care system (Sartorius, 2007). For this particular group of Chinese men, all disorders/diseases are subject to the same level of stigmatisation. What's more, the stigma does not stop with the person suffering from ill health, but is pervasive, in as much as the stigmatising effect is believed to affect immediate and even remote family members and friends. In an attempt to protect family and friends from the burden of their health problem(s), and to preserve a sense of social cohesion, these Chinese men do not discuss concerns they have about their health and wellbeing, and they do not actively engage in help-seeking behaviour.

### **6.3 Illness Stigma: Hegemonic Masculinity**

This particular group of Chinese men's felt vulnerability to illness stigma seemed to be bound to expectations about how men (predisposing) should manage their health; and perceptions of risk, which emphasised resilience, self-reliance, and stoicism. These Chinese men's ability to withstand ill health seems to supersede any concerns they have about their health. There was a shared understanding for the need of secrecy and denial about possible health concerns. These findings could be understood as a way in which these Chinese men manage the balance between self-reliance and a sense of vulnerability (Nobis, & Sanden, 2008).

The need to maintain a sense of normality about their health could be viewed as an expression of these Chinese men's sense of masculinity; which seemed to be a significant driver to maintaining the perception of risk of illness stigma. Also, these Chinese men's sense of masculinity seemed to inform their health behaviour, as they purposely avoid engaging in help-seeking behaviour (e.g. talking about health concerns, and accessing health care services). This finding has resonance with the concept of hegemonic masculinity

(Sabo & Gordon, 1995; Gerschick & Miller, 1994). Critics argue that the underlying concept of hegemonic masculinity is conflicting in terms of being framed within a '*heteronormative conception of gender*' that tends to oversimplify gender diversity and to ignore individual differences (Demetriou, 2001). It is argued here that this view is not substantiated, as the qualitative methods used in this study ensured that every effort was made to explore all participants' accounts, which identified their understandings and their perspectives, and took account of individual differences and lived experiences. As the analysis was firmly embedded in participants' narratives, we assert that these Chinese men's sense of masculinity is consistent with the concept of the hegemonic masculinity. This finding adds to the risk perception literature, by offering insights into the way in which these Chinese men construct their personal perceived risk, and showing how a socio-culturally prescribed sense of masculinity directly impacts on health decisions and help-seeking behaviour.

Strong culturally held beliefs that support these Chinese men's sense of masculinity are further complicated by a commonly held view that if one was '*diagnosed with a disease*'; there is a very real prospect of ostracism and social isolation. The significance of this finding is accentuated for these Chinese men, who report that they already feel '*cut off*' and '*isolated*' from the wider community in Ayrshire. The prospect of being shunned by your own small ethnic group acts to further discourage these Chinese men from actively seeking medical attention. The analysis suggests that these Chinese men experience a considerable level of fear and anxiety about the perceptions of other people (public perceived stigma). In addition, the analysis suggests that it is this enmeshed fear, and vulnerability to illness stigma that pose the greatest risk to these Chinese men's health, as it facilitates denial of an impending health crisis, and delays help-seeking behaviour and treatment for potentially serious health complaints.



The literature has previously reported men's tendency to delay health help-seeking as being largely attributed to masculinity (Corbie-Smith, et al., 2010; Hammond, Matthews, & Corbie-Smith, 2010; Powell, Adams, Cole-Lewis, Agyemang, & Uptom, 2016). The findings from the present study add to this body of work by documenting the relationship between these Chinese men's sense of control, negative psychological sequelae, and their risk perceptions, which are influenced and maintained by predisposing factors (e.g. gender, ethnicity, socio-cultural beliefs), that act as powerful barriers to health help-seeking behaviour.

#### **6.4 Illness Stigma: Low Personal Perceived Risk**

The analysis suggests that the Chinese women who took part in this study have a low personal perception of risk of illness stigma. This group of women understand their low-risk perception to illness stigma in terms of their own emotional and cognitive response to ill health (Figure: 3). These Chinese women seemed to be more willing and able than the Chinese men who took part in this study to accept the experience of ill health and to acknowledge the futility of maintaining the cultural norm of fostering negative emotions associated with illness. By responding in a more positive way to the experience of illness (emotional acceptance), using humour (cognitive resource), and laughter (behavioural coping response) as a device, women were more able than men to refute the Chinese custom of '*losing face*'. This has afforded this group of women the opportunity to integrate more positive emotions, cognitions, and health behaviours into their life, thereby enabling them to cope, and adapt more resourcefully to illness than their male counterparts.

Previous studies have found strong correlations with humour, good self-efficacy, and resilience (Kuiper, 2012; Evans-Palmer, 2016). Humour has also been found to be a functional device to attenuate negative emotions and to alleviate distress (Crawford & Caltabiano, 2011) while promoting emotional well-being (Windle, 2011; Ibarra-Rovillard & Kuiper, 2011). These findings add to our understanding of the differences between the

Chinese men and women who took part in the present study, and the role of cognitive and behavioural strategies that can serve as a protective mechanism to buffer culturally prescribed illness stigma in this particular group of participants.

The analysis offers weaker evidence to suggest that these Chinese women use positive reappraisal and problem-focused coping strategies to infuse cultural health beliefs with more positive meaning. Conversely, the negative emotions and negative health cognitions seem to maintain and perpetuate these Chinese men's sense of vulnerability to a felt risk of stigma, which inhibit their ability to engage in help-seeking behaviour, placing them at greater risk of experiencing unmet health care needs compared to the Chinese women who took part in the present study. A strengths-based cognitive behavioural model (Padesky & Mooney, 2012), may be helpful for clinicians interested in supporting these Chinese men to adapt and cope more effectively with the challenges of ill health (Chapter 8, Section: 8.4.2/5).

The findings support previous literature by demonstrating the role of emotion in risk perception (Zajonc, 1980; Slovic, Finucane, Peters, & MacGregor, 2004a). The findings add to this body of work by mapping the interaction between positive emotions, positive cognitions, and health-promoting behaviour (e.g. laughter), which seems to serve a protective function; reducing this group of women's risk of experiencing a felt risk of illness stigma; while promotion advantages to health (Table 1). Similarly, this study demonstrated the utility of maintaining cultural norms of negatively labelling illness, and the continuance of the belief of 'losing face' (negative cognitions), on emotions (perpetuates the experience of fear and anxiety), health behaviour (do not engage in help-seeking behaviour), and risk perception (high risk of experiencing an internalised form of stigma). Additionally, the analysis demonstrated an interaction between emotions, cognitions, and behaviour, and offered a means to understanding the crucial ways in which these Chinese men's personal perception of risk differ from Chinese women's risk perceptions.

**Table 1 Risk of Illness Stigma: Differences between Chinese Participants**

Participants	Emotions	Cognitions	Behaviour	Consequences
Chinese men	Fear Anxiety	“Lose Face”	Avoid talking about health concerns.  Do not engage in help-seeking behaviour.  Mask any symptoms experienced (e.g. pain/).	Experience a felt risk of illness stigma and unmet health care needs.
Chinese Women	Emotional acceptance	Humour	Laughter. Actively engage in discussions about health concerns.  Actively seek help.	Protected from experiencing a felt risk of illness stigma.

## 6.5 HIV-Related Stigma

David’s (Black African) risk perception differed from that of these Chinese men in terms of perceiving his community to be at high risk of experiencing HIV-related stigma (Chapter 6: Section: 6.2). David’s generalised perception of HIV-related stigma was equal to his personal perception of risk. David explained that HIV-related stigma was directly related to his community’s high level of awareness of HIV, which he believed was directly proportional to the high prevalence of HIV across the African continent. David had a heightened sense of awareness that his community carried a disproportionately higher burden of HIV than other populations. This has created a great sense a fear, and anxiety about possibly experiencing HIV-related stigma.

In David’s words:

*...see back home, in Africa, sexual health diseases and HIV things like that are a big problem, there and here, there is very much stigma attached to it. Definitely, in Africa, sexual diseases have a stigma attached it, very afraid...*

(David, Black African)

David argued that the Black African community does not attend general or sexual health services in Scotland based on a “*fear of being stigmatised*” and concerns about being judged by health service providers and the wider community for “*bringing disease into the country*”.

As David says:

*...see, well, normally in my country sexual health diseases have very much stigma attached to it. Definitely, in Africa, sexual diseases have a stigma attached to it, very, very afraid to go to hospital, for HIV and things like that. We don't want to be seen to have a sexual problem here, and we feel very frightened, so that's why we don't go to the doctors.*

(David, Black African)

This participant's risk perception was experienced as anxiety about being stereotypically labelled as HIV positive, and as a fear of experiencing stigmatising attitudes from members of the general public, and discriminatory behaviour from health care professionals (public-perceived stigma). The perception of risk of experiencing stigmatisation by health care professionals and the wider community remains a source of considerable fear and anxiety for this very vulnerable group of people. Thomas's narratives serve to illustrate how vulnerable his community feel about being stigmatised, he said.

*Africans and sexual diseases have a stigma attached to it, very afraid to go to hospital, for HIV and things like that... we feel very frightened about this stigma...*

(David, Black African)

HIV was understood to be a sexually transmitted disease, as such, the community remained fearful about the implications for their personal character and status. This finding has resonance with the work of Burns and colleagues (2007), who set out to identify the

determinants affecting HIV service utilisation among Black Africans residing in the UK. This study reported that participants were very aware of HIV, and had an increased sense of awareness of HIV which was related to participants' country of origin. The fear of stigma was acknowledged as a major barrier to HIV screening and HIV services. Analysis from the present study shows that David (Black African) was fearful of HIV-related stigma, and remained anxious about experiencing stigmatising attitudes, and discriminatory behaviour; which, restricted his uptake of local sexual health screening programmes, and the use of general health care services.

### **6.6 Feeling a Sense of Risk**

The analysis offers insights into how the Black African participant constructed his personal perception of risk, which supports previous work associating risk of stigma to culturally defined stereotyped beliefs (Link & Phelan, 2001; Kang et al., 2005; Campbell & Deacon, 2006). The sense of vulnerability to HIV-related stigma echoes these Chinese men's perceived risk of illness stigma, in that both groups of men experienced a strong emotional response (i.e. fear and anxiety) when they consider the prospect of being labelled. This finding supports previous work on affect and decision-making, which assert that visceral emotions of fear and anxiety play a role in the experience of risk as feelings (Zajonc, 1980; Slovic, Finucane, Peters, & MacGregor, 2004a). In addition, the anxiety and fear associated with being labelled and of possibly experiencing either illness stigma or HIV-related stigma were directly related to the men's decision not to access health care services. The results add to this body of work by presenting this group of men as purposive and decisive agents, who construct and explain their risk perceptions within their own cultural context, and experience risk as a feeling. In addition, it is argued that risk perceptions and help-seeking behaviour for these men are inextricably rooted in a complex interaction between individual-level characteristics, such as culturally held beliefs, normative behaviour, and emotions.

## **6.7 Internalised/Felt Stigma**

The analysis found that Black African and these Chinese men's personal perception of risk was similar in terms of a felt or internalised form of stigma. This internalised form of stigma seemed to be entrenched in ethnocultural beliefs and by endorsing stigmatising attitudes and norms of their respective countries of origin. Further, these Chinese and Black African men's perceptions of risk of stigma are not simply the consequence of unfounded fears or unchecked emotions, but are bound to sets of consistent health beliefs, and embedded in cultural normative practices.

Illness stigma and HIV-related stigma were also similar in terms of being internalised (felt stigma), rather than being the resultant effect of personally experiencing stigma or any form of discrimination. This felt stigma carries with it a sense of social separateness from their immediate and wider community, which served to disempower these men, negatively impacting their health behaviours (not seeking help or accessing health care services), which in turn increases their risk of experiencing poorer health outcomes and health inequalities. The findings support previous research that assert that emerging evidence indicates that stigma meets the criteria to be considered a fundamental cause of health inequalities (Major & O'Brien, 2005), that it influences health outcomes through multiple mechanisms (Berkman & Kawachi, 2000), and inhibits access to health care (Hatzenbuehler et al., 2011).

## **6.8 Framework for Stigma**

The personal perceptions of risk of stigma experienced by these Chinese and Black African men can in part be conceptualised within The Framework for Stigma (Phelan, Link, & Dovidio, 2008). The components include labelling, negative associations conferred upon those who are labelled, social separateness and consequences (Table 2). While our findings uphold the social elements of this model, they also extend its boundaries by situating stigma within the individual. For example, the findings argue that personal perception of risk of

stigma has emotional (e.g. anxiety and fear), cognitive (beliefs and attitudes), motivational (e.g. no intention of seeking help), and behavioural components (e.g. intentionally do not actively engage with health care services in Ayrshire), that direct toward understanding risk perception within a heuristic model (Chapter 7: Section: 7.4.1 – 7.4.5). In addition, these men's socio-cultural norms were found to exert an effect on how they made sense of and estimated their risk of stigma compared to other BME groups, thereby offering support for probability theory (Slovic, Finucane, Peters, & MacGregor, 2004b).

**Table 2 Conceptual Framework for Stigma**

<b>Components of the Model</b>	<b>Chinese men</b>	<b>Black African Man</b>
<b>Labelled</b>	Being labelled as ill	Being labelled as HIV+
<b>Negative Stereotyping</b>	Having ill or failing health has implications for personal character and status	Having a sexually transmitted disease has negative implications for personal character and status
<b>Social Separateness</b>	Cultural norm of ostracising ill person from family, the Chinese community, and the wider community.	Cultural norm of being shunned by the community in Africa.
<b>Consequences</b>	Perceptions of loss and discrimination. Men do not talk about their health concerns or seek help for symptoms. Increased risk of health inequalities and poorer health outcomes	Perceptions of loss and discrimination. Does not access health care services. Increased risk of health inequalities and poorer health outcomes

## 6.9 Heart Disease and Diabetes

Within participants' accounts were considerations of risk of heart disease and diabetes. The risk of heart disease was found to be associated with modifiable lifestyle factors (smoking & high fat diet) and therefore understood to be a highly preventable disease. Joseph, like other fellow participants, reported having a strong family history of heart disease and diabetes. A strong family history was considered as having '*two or more close family*

members'. The findings overall suggest that having a known familial history was not associated with greater perceived personal risk for heart disease. To illustrate Joseph said:

*My dad died with heart disease, and he was the age I am now 52, and my mum has it too. My brother has just been told he has diabetes, but that was after being ill for a long time, but he's okay. But my dad smoked and mums diet doesn't change from when she was in India.*

(Joseph, Indian, Sikh)

Joseph's low perception of personal risk for heart disease was echoed in his reply to a line of enquiry about any previous attempts to have his heart checked, he answered:

*No, no I haven't, I'm healthy. See I don't smoke and I tend to cook with olive oil now, where the older generation still use a lot of hot, oily, spicy foods. They eat lots of butter, lots of fatty foods, they eat lots of butter in the lentils and overall in food.*

(Joseph, Indian, Sikh)

There were strong indications within the Indian community's accounts to suggest that they distanced themselves from the 'type' of person likely to develop heart disease. For example, Joseph's low personal perceived risk for heart disease was achieved by identifying and evaluating differences in his lifestyle (e.g. smoking, exercise, low-fat diet), against those of his family. This finding supports the concept of 'coronary candidacy' (Chapter 1: Section: 3.1; Chapter 6: Section: 6.6), which led this group of participants to perceive that heart disease did not pose a risk to their personal health, despite having a strong family history. This finding is consistent with the literature examining personal perceived risk for coronary heart disease (CHD). McKenzie (2009) found that participants described those they



considered to be at risk of CHD with ease. Despite all participants readily acknowledging they fulfilled much of their own criteria for those being most at risk of developing the disease, they had a low personal perceived risk. An earlier study investigating the experiences of women who had recently suffered a heart attack found there was evidence of an inverse link between knowledge and perceived personal risk. Women in this study regarded themselves as very knowledgeable about heart disease, but all underestimated their general risk and personal perceived risk of developing heart disease and having a heart attack; despite having a strong family history (McKenzie, 2005). Conversely, Joseph concluded that he was at risk of developing diabetes, after becoming aware of his brother's recent diagnosis of Type II diabetes. He says:

*Now that I know, that my brother has diabetes, it has made me think, I might get it. So I asked my brother what are the signs, what I should look out for.*

(Joseph, Indian Sikh)

We can imply from Joseph's narratives that his personal perceived risk for diabetes is greater than his perceived risk for developing heart disease. This result suggests that Joseph holds contradictory views about his personal perception of risk to his health, despite having a strong familial risk. The cognitive process that led Joseph to determine his personal perceived health risk included assessing the level of similarity and dissimilarity in age and dietary factors; and by evaluating the extent to which his own lifestyle poses a risk to his vulnerability to heart disease and Type II diabetes. These cognitive processes served as a trigger that prompted Joseph to engage in help-seeking behaviour, evidenced by him enquiring about the symptoms of diabetes so that he felt equipped to detect early signs of the disease.

Findings from the current study show that low perceived personal risk may be related in part to ineffectual health promotion messages of high susceptibility of heart disease within the Asian community, and how this relates to preventative health behaviours and family history. However, the findings are more complex, as participants, who had at least two members of their family diagnosed with heart disease, also had relatives who were living with Type II diabetes. This finding is borne out by James' narratives, who, like his fellow participants had a greater perceived personal risk of developing diabetes than for developing heart disease; despite the equal familial risk. This result supports the view that people can hold contradictory views about perceived risk particularly with regard to family patterns of illness as being important in the origins of specific disease processes (Davison, Davey Smith, & Frankey, 1991). It is not possible to argue that perceptions of personal risk accurately reflect participants' actual risk or their exposure to established risk factors.

These findings demonstrate the complex cognitions involved in perceived risk for heart disease and diabetes. Additionally, it informs us of how knowledge of family history could possibly result in a lack of perceived risk, or promote increased awareness and susceptibility. The author argues that these findings have implications for health promotion campaigns. There is a strong need to implement an aggressive campaign to 1. Raise awareness of heart disease in the Asian population, 2. Provide culturally sensitive information about modifiable risk factors, and how these relate to familial risk, 3. Inform the Asian community of screening programmes for heart disease, diabetes and relevant health promotion resources that are culturally sensitive, using media that would match participants level of literacy and linguistic competency.

### **6.9.1 Breast and Cervical Cancer**

There was evidence to suggest that all of the women who took part in this study assessed their personal risk of breast cancer to be marginally higher than their risk of cervical cancer,

due to being more knowledgeable about cervical screening programmes. There was a shared perception among this group of women that breast cancer did not pose any more of a risk to their health, than it does for women from the wider population; despite breast cancer being a primary form of cancer in BME women (Fenton, 2015), and one of the few cancers which can be detected in its preclinical stage (Cancer Research UK, 2016).

Situated within the women's narratives were indications to suggest that they were concerned about their risk of breast cancer. Participants reported recognising the importance of breast self-examination (BSE), as a means of early breast cancer detection, but most stated that they lacked knowledge about how to self-examine, and were uncertain about what they should be looking for. Margaret explains:

*...we don't know how to look out for lumps, or if you've got a problem in your breasts, we don't know when it is really important or to just ignore it, it might be a mild infection, we just don't know what to do or how to examine ourselves and if you do find something what do you do and where do you go'.*

(Margaret, Thai)

Current health guidelines suggest that women should know how their breasts normally feel and report any breast changes promptly to their health care providers. Female participants in the current study report recognising the importance of breast self-examination (BSE), but most stated that they lacked knowledge about how to self-examine and had concerns about 'what they should be looking'. This finding suggests that a lack of knowledge about BSE techniques directly influences this group of women's risk perceptions. The association between a lack of knowledge about BSE and a low-risk perception of breast cancer can be

A qualitative study exploring the experiences of access and pathways to health care among BME community groups residing in Ayrshire

considered as a critical barrier to early detection of breast cancer and effective early intervention.

Aware of the implications of late detection, all of the women expressed an interest in BSE training, which would provide them with the knowledge and skills to detect early changes in their breast tissue. Meeting this need could facilitate the signposting to mammography screening services if required, and to other sexual or general health screening services. This would afford the opportunity to not only detect and treat early physiological changes but could help to build rapport, strengthen community links, and lay the foundations of trust and confidence in the NHS across the county (Chapter 8: Section: 8.4.4/2).

Analysis showed that all of the women who took part in this study were generally more knowledgeable about cervical cancer than breast cancer. Women did not explicitly discuss their perception of risk for cervical cancer, but rather, talked about their knowledge and awareness about the purpose, and the recommended frequency by which cervical smear tests should be sought. To illustrate, all of the women explained that this screening test helped to “*detect for any changes and for cervical cancer*”, but there was much less agreement about the frequency of which the tests should be carried out; estimated time varied from 2 - 10 years. All of the women said that they attend for a smear test, when “*they get a note from the doctor*”; and all of the women recognised the importance of regular screening. The most commonly cited barriers that prevented women from getting a smear test were “*fear*” and “*embarrassment*”. The overall results show that cervical screening services programmes across the three local districts of Ayrshire are successful. However the variability in estimated frequency by which screening should be conducted, suggesting there are latent barriers to contacting patients, or possible variations in the delivery and provision of cervical screening services.

### 6.9.2 Nasopharyngeal Cancer and Liver Cancer

Incidence rates for nasopharyngeal (NPC) and liver cancer are high in some areas of China, particularly in southern China and in the Cantonese populations; and are now on the increase in Scotland, due to greater numbers of Chinese migrants. Women from the Chinese community expressed their concerns about nasopharyngeal cancer (NPC) and liver cancer. Their personal perceived risk was equal to their general perceived risk of developing both of these diseases, due to maintaining culturally specific dietary factors (e.g. eating salty fish). Despite the high prevalence rate of NPC and liver cancer within the Chinese community, there were expressed concerns about GPs not being aware of their increased risk, which heightened their sense of vulnerability to experiencing poorer health outcomes. This increased sense of vulnerability was intensified due to concerns about physicians in Scotland lacking knowledge about how to '*diagnose and treat*' NPC; and concerns that the "*gatekeepers*" (GPs working in primary care services), to specialist services are unaware of the symptoms related to NPC, which would delay timely treatment. These concerns have led participants' to "*returned to Hong Kong for treatment*", as "*Hong Kong is renowned for treatment of NPC*".

### 6.9.3 Candidacy and Participants' Personal Perception of Risk

The concept of candidacy (Chapter 1: Section: 1.4.1.2) is worth considering in the light of the participants' personal perception of risk. Candidacy can be understood as a device that helped participants to make sense of and assess their personal risk. For many participants' their personal perception of risk was framed within predisposing factors (e.g. socio-cultural beliefs, and norms), which had both a predictive as well as a retrospective dimension. The predictive element was the high likelihood of experiencing stigma (for these Chinese and Black African men), or for other participants, the high risk of developing a particular disease (e.g. Type II diabetes). The retrospective element also seemed to be driven by predisposing factors (e.g. ethnicity & gender), and health behaviours (e.g. lifestyle factors) to determine

personal perception of risk for breast and cervical cancer, nasopharyngeal and liver cancer.

These findings extend the concept of candidacy to include stigma, breast and cervical cancer, Type II diabetes, and nasopharyngeal and liver cancer. Critically, the concept of candidacy tells us nothing about how female participants assessed their risk of developing breast and cervical cancer, or to understand the contradictory health beliefs found in an Indian male participant's narratives regarding the high perception of risk for Type II diabetes, and low risk for heart disease despite having a strong familial history of both diseases.

Notwithstanding the contribution of candidacy to understand participants' risk perceptions, the analysis suggests that the concept has too narrow a focus, as it is based on a limited set of criteria (i.e. physical appearance, social information & personal information) (Davison, Smith, & Frankey, 1991). Further, the concept is limited in terms of failing to capture the cognitive processes that enabled participants to actively construct their personal perception of risk and to explain why participants simultaneously overestimated and underestimated their risk in light of other relative threats to their health and wellbeing. These limitations direct towards understanding personal perception in terms of neurocognitive models of risk perception (Chapter 6: Section: 6.9.4).

#### **6.9.4 A Neurocognitive Perspective of Participants' Risk Perception**

The results indicate that despite important differences existing in relation to participants' risk perceptions, there seem to be similarities in the way in which participants from different BME groups made sense of, and understood their personal risk. There was strong evidence across participants' accounts to suggest that intrapersonal factors (i.e. health beliefs, attitudes, emotions, and behaviour), played an important role in how they made sense of their personal perception of risk. These cues offer support for the role of a dual cognitive processing system which functioned to help participants understand and assess their level of risk compared to the wider population. To illustrate, the normative rules (e.g. probability,

rationality, and risk assessment), which governs the analytic processing system seems to have provided a basis from which rational judgements were made about risk. Working in parallel, the experiential system seemed to have served as a means by which participants could quickly sense, or feel the risk. As the experiential system is aligned to the analytic system (Slovic, Finucane, Peters, & MacGregor, 2004b), it is argued, that it is through the interaction between these two processing systems that participants were able to assess the probability or likelihood of experiencing very specific risks to their health and wellbeing.

There was strong evidence within the narratives of these Chinese and Black African men of a heavier pull on the experiential system, compared to other participants, due to the high level of affect and emotion detected in their accounts. In contrast, the analytic system seemed to be the most dominant processing system found in the narratives of all of the participants who took part in this study, due to the probability judgements and logical reasoning detected in their risk assessments. These findings support earlier studies, which argue for a dual processing system to risk perception (Slovic, Finucane, Peters, & MacGregor, 2004b). Yet, this modelling falls short of explaining the process of how participants made sense of their risk. This raises questions about the primary cognitive processes underpinning and linking the dual process systems. More recently, researchers have characterised the probability judgements people make about their risk by means of heuristic processing (Slovic, Finucane, Peters, & MacGregor, 2004b; Damasio, 1994). Evidence for the role of heuristic on participants' personal perception of risk comes from strong evidence within the data to suggest that symbolic knowledge based representations, and inferential rules (or heuristics), were used. This was evidenced by examples of participants' making comparative judgements between their individual-level predisposing characteristics, health behaviours, and their risk perceptions. This evidence directs towards understanding participants' personal perception of risk by means of a heuristic model. To examine this assertion, a negative case analysis was conducted (Chapter 6: Section: 6.8),

A qualitative study exploring the experiences of access and pathways to health care among BME community groups residing in Ayrshire using the same CBT methods previously described (Chapter 3: Section: 3.6).

### **6.9.5 Negative Case Analysis 2**

A negative case analysis was conducted (Chapter 2: Section: 2.9.2), as there was considerable variability within and across participants' accounts. The findings from which upheld earlier analysis of the data described above and adds to our understanding of the primary cognitive process involved in participants risk assessment. Using cognitive behaviour functional analysis (CBT/FA), it was possible to identify specific cognitive heuristics used by participants which seemed to have been strongly influenced by participants' predisposing characteristics. It was also possible using a CBT approach to identify a range of cognitive errors (Chapter 7: Section: 7.3.5; Appendix: 7: Table D), which helped to explain why, in the light of other equally possible risks, participants' judgements about risk were limited, were assessed with a high degree of certainty, and judged as factual, without questioning the validity of their risk perceptions. In light of these findings we are directed towards a heuristic model (Chapter 7: Sections: 7.3.1-7.3.4; Appendix 7 Table C), to understand the ways in which participants' made sense of their personal perception of risk, and to argue for risk perceptions to be considered as a complex and multidimensional concept.



## Chapter 7

### 7.1 Discussion

This study aimed to gain insights into the perspectives of BME community groups' experiences of accessing general and sexual health care services in Ayrshire. It is important to stress that this study does not seek to generalise out with the study's population, and in some cases, it is not possible to generalise out with an individual participant's perspective. Evidence from the literature suggesting that some BME groups are disadvantaged in obtaining full and equal access to health care (Fischbacher, Bhopal, Steiner, Morris, & Chalmers, 2009), are at risk of experiencing socio-economic disadvantage, racism and discrimination (Rogers & Pilgrim, 2010; Nazroo, Iley, Pilgrim, Rogers, & Pescosolido, 2011, pp. 80-102); and some groups experience poorer health outcomes compared to the wider population (Psarros, 2014; British Heart Foundation, 2015; Bhopal et al., 2005; Simpson et al., 2015; Deepa, et al., 2015; Scottish Public Health Observatory, 2015). However, there was no evidence within participants' narratives to indicate that they experienced any level of discrimination, or racism at an individual, community, or organisational level (e.g. NHS). As no socio-demographic information was gathered, it is not possible to state with any level of certainty if participants were subject to socio-economic disadvantage, reduced access to employment and/or housing; or if any of these factors influenced their actual ability to access care. There was also no evidence to indicate that participants' perceived these factors as risks to their health, as barriers to care, or increased their perceptions of a need to access health care services. The main results of this study are illustrated through the use of four super-ordinate themes: 'It's a Trust Thing', 'Mind the Gaps', 'Sexual Health: a Culture of Silence' and 'Personal Perception of Risk'.

### 7.1.2 It's a Trust Thing

Studies indicate that having access to a regular source of health care (RSC) increases the likelihood of receiving better-coordinated care, better treatment options for chronic and acute health conditions, fewer delays in care, and access to preventive care (Turbitt & Freed, 2016). A barrier to a RSC identified in the literature is low levels of trust. Symonds, Lord, Mitchell, & Raghava (2012), suggest that women from BME groups have lower levels of confidence and trust in the health care system than Caucasian women. There is currently a paucity of literature exploring trust in a health care context among Scotland's BME communities, and there remains a need to understand the process by which trust and distrust are realised.

In the present study, a diminished sense of trust in general practitioners (GPs) in Ayrshire reflect individual characteristics, such as negatively held attitudes, and low expectations of care even before participants arrived in Scotland (Chapter 3; Sections: 3.2; 3.3). Analyses found an association between participants' individual-level characteristics (predisposing factors), and structural level factors (at the provider, and system level), which reinforced pre-existing beliefs about the accessibility and the quality of health services in Ayrshire. These factors led to a distrust of the health care system, which informed participants' decisions about seeking alternative pathways to health care. Analyses also found a cluster of strong antecedents to suggest that participants' trust in primary care services in Ayrshire, the NHS in general, and trust in Western medicine (Chinese participants only), was exceptionally low. Health communication occurring at the physician-patient level seemed to play a central role in the breakdown of the therapeutic relationship, and trust for this particular group of participants. This raises concerns about variations in implementing PCC approaches in Ayrshire (Bergman & Connaughton, 2013; de Silva, 2014), which impacted on the present study's population from engaging in shared decision in the clinical interview, and thereby increased the risk of experiencing poorer health outcomes for some participants (Chapter 8:

Section: 8.1.2.2.3). The findings suggest that interventions aiming to improve the quality of health communication in clinical practice may be an important opportunity to reduce barriers to care for the study's participants (Chapter 8, Section: 8.4.2/3). In addition, it seems that the accumulative effect of a range of concerns, including concerns about GPs' level of clinical competency, tipped the decisional balance (Janis & Mann, 1977; Miller & Rollnick, 2002; Prochaska et al., 1994), to inform participants' decisions not to engage with health care services in Ayrshire now, or in the future. This finding supports earlier studies which found that trust in public services are compromised when there are concerns about technical competence, openness, and health care providers who do not demonstrate impartial concern for the patient's well-being (Davies, 1999; Mechanic, 1996; Coulson, 1998). Low levels of trust of primary care services demonstrate the relationship between trust and dissatisfaction with care (Chapter 3: Section: 3.2 - 3.4). Factors leading to dissatisfaction with care have been previously documented in the wider health literature (Krupat, et al., 2001; Keating, Green, Kao, Gazmararian, Wu, & Cleary, 2002), with trust cited as a primary factor. Yet, authors fail to report what constitutes a sense of trust or to show how trust and dissatisfaction with care are conceptually similar and dissimilar. The present study goes some way to addressing these concerns by outlining participants' understandings of the basis of their diminished sense of trust (e.g. not feeling listened to, and needs not understood).

A distrust of the NHS was evident across all participants' accounts (Chapter 3) but experienced much stronger by David (Black African). It is argued that David experienced distrust as a felt expression of an unequal division or balance of power, in which confidential medical records are subject to breach in his native homeland (Chapter 3; Section: 3.3), which led him to have similar expectations about the management of care in Scotland. Power differentials in health have been reported in the wider health literature (WHO, 2002; Farmer & Sen, 2003; Jones, 2014), and interventions to address unequal power differentials

are a current focus in health research (e.g. PCC approaches) (Picker Institute, 2015); yet little is known about how BME patient groups perceive imbalances in power, how this exerts an effect on trust, and a willingness to engage with unfamiliar health care systems. This result supports studies which suggest that key barriers to access, shared decision making, and patient-physician communication is distrust in the medical system (Newlin Lew, Arbauh, Banach, & Melkus, 2015; Ratanawongsa et al., 2013; Burkett et al., 2015). The evidence suggests that this cohort of participants from various BME communities in Ayrshire are not benefiting from advancement in policy and service development (Scullion & Morris, 2009). This finding supports previous research suggesting that some patients are not benefiting from accessing care in Scotland (Fife, MacMillian, Fleming, & Callaghan, 2011). Some organisations suggest that policymakers should focus attention on identifying and addressing the social determinants of health, in an attempt to resolve possible underlying structures that perpetuate inequalities in health that BME groups reportedly experience (Race Equality Forum, 2015; Joseph Rowntree Foundation, 2016). Other writers have argued that there are organisational and structural barriers to health (Nazroo, 1998; Holland & Ousey, 2011; Weerasinghe, 2012). Here it is argued that population and individual level characteristics interacted with structural factors (occurring at the provider and health system level), which led to low levels of trust in Ayrshire and Arran Health Board. The resultant effect influenced participants' behavioural intentions (not to access services) (Chapter 8: Section: 8.1.2.2.2), which may increase the risk of some participants to experience poorer health outcomes (Chapter 8; Section: 8.1.2.2.3).

Despite participants from the Chinese community having a high level of trust in the Western medical approach in their homeland (Chapter 3; Section: 3.1), a high level of distrust in the Western medical approach used in Scotland was found (Chapter 3; Section: 3.4). Trust in Western medicine prescribed in Scotland was compromised by participants reflecting on their personal experience of not gaining any positive health benefits and the perception that

technologically advanced diagnostic tests were not readily available, or easily accessible.

Entrenched within participants' narratives were beliefs about the efficacy of prescribed medication (e.g. low quality, inadequate dose, and lack of potency), which were considered to be ineffective in the treatment of systemic health problems. The potency of prescription drugs and the restricted narrow focus of health assessment measures used in Scotland were considered to be ineffectual, and deleterious to health. Previous studies have reported a trend in the literature showing low confidence and trust increase when cultural health beliefs are contradictory to conventional health care guidelines (Thompson, Valdimarsdottir, Winkei, Jandorf, & Redd, 2004; O'Malley, Kerner, Johnson, & Mandelblatt, 1999; Peragallo, Fox, & Alba, 1998). Critically, a scaling measure was used to assess medical mistrust, and there were omissions in the cited papers referring to specific culturally held beliefs of participants, thereby putting into question the ecological validity and transferability of these results to individuals from diverse ethnic groups and socio-economic backgrounds. It is here argued that the findings from the present study add to the paucity of literature by identifying specific health beliefs (predisposing factor), and subsequent health behaviours of this particular group of Chinese community members. This finding underscores the importance of documenting characteristics of specific BME participants so as to inform health practitioners working in primary care services to 1. be aware of the health beliefs and health practices of some Chinese patients; 2. facilitate discussions about concerns they have about Western approaches to care; 3. provide appropriate medical advice and support that would be more meaningfully understood, and aligning the approach used to meet this group of patients' needs. This information may help support primary care physicians attempts to develop their own health literacy, to enable them to more readily defer to this group of patients' preferences, as a preliminary step toward building the foundations of trust (Légaré et al., 2012a, 2012b). The results supports earlier studies (Heitanen, Aro, Holli, & Absetz, 2000; Liang et al., 2002), and adds to the trust literature by showing that despite the experience of a diminished sense of trust arising from different sources, the outcome of the interaction

between a range of individual-level characteristics, and provider-level factors, exert a similar effect on participants' health behaviour; avoidance of primary care services and the wider health development (NHS) (Chapter 8: Section: 8.1.2.2.2).

While research suggests that patients' trust is desirable because it is associated with improved health outcomes (Golin, DiMatteo, & Gelber, 1996; Greenfield, Kaplan, & Ware, 1985; Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Mahler & Kulik, 1990), critics argue that patients who trust less, especially in "*managed care settings*" (including the primary care context), avoid the pitfalls of the paternalistic model that may still be present within current medical practice (Gatter, 2004; Edwards & Elwyn, 2006). It is argued here that the diminished sense of trust in primary care services and a distrust of the NHS found within and across participants' accounts, may have a protective function, such as maintaining participants' sense of autonomy and shielding them from traditional paternalistic models of care. Conversely, the protective effects of not trusting may be lost by participants' decision not to engage with the health care system. In addition, the analysis showed that trust, a diminished sense of trust and distrust are underpinned by rational and moral processes, and are inextricably bound to participants' expectations, and relates to participants' willingness to be involved in medical care. It is argued that the present study adds to the trust literature by presenting a fine-grained analysis of participants' accounts (Chapter 3), which directs toward a heuristic model of trust (Chapter 7; Section: 7.1.3-7.1.5).

### **7.1.3 Toward a Heuristic Model of Participants' Trust**

The analysis suggests that trust (in health care services in the country of origin), a diminished sense of trust in primary care services, and distrust of the NHS, in general, are similar in terms of being understood as expressions of expectations of care (predisposing factors). Participants' expectations were found to be underpinned by moral judgments (e.g. values, health attitudes, health beliefs and norms), and guided by rational thought

processes, and cognitive errors (Chapter 3; Section: 3.6). It is these critical predisposing factors that served to reinforce existing negative thoughts about primary care services and led participants to draw generalised conclusions about the quality of care within the NHS. The outcome of the interaction between these factors had a similar effect on participants' health behaviour, through avoidance of primary care services and the wider health development (NHS). These findings add to the existing literature by presenting a comprehensive appraisal of trust and charting the process of trust, a diminished sense of trust, and distrust, and how these relate to participants' willingness to engage with health professionals and health care systems. These findings add to our understanding of the role of value judgments (e.g. attitudes and values), and expectations of care that led to concerns about GPs competency, and a diminished sense of trust and dissatisfaction with care (which for some was based on a single consultation). This evidence strengthens the view that trust can be conceptualised within a heuristic model, which capture different sources of expectations as understood by participants.

#### 7.1.4 Heuristic Model of Participants' Trust

The heuristic model of participants' trust presented below outlines the most salient factors found in analysis, which informed participants' judgements and their decisions. This model emphasises the '*fast and frugal*' nature of heuristics, while, at the same time outlines the way in which participants made sense of trust, and trustworthiness, to make rational choices about meeting their health care needs.

- **Rational Trust:** With the exception of David (Black African), participants accounts suggest that they consciously took into account the expected costs and benefits when they decided whether to trust or not and made reasonable decisions to meeting their health care needs; a. Not to engage with the NHS b. to return to their respective country of origin to access a health care system they trust.

- **Moral Trust:** values, attitudes, beliefs and norms were found to be the cornerstones to participants' expectations of care when these were upheld, higher levels of trust were experienced (high level of trust in physicians & health care system and approach in their respective countries of origin). Conversely, when these same values were perceived as being breached (as evidenced by participants' accounts of using primary care services); participants experienced a diminished sense of trust in primary care services and/or distrust of the NHS in Ayrshire
  
- **A Generalised Diminished Sense of Trust/Distrust:** Participants use the cognitive process of generalisation to make sense of their experience, which informed their decision not to access healthcare in Scotland. i. Diminished sense of trust in primary care services was generalised to a loss of trust sense of trust in the NHS as a system; ii. Distrust in a geographically distant and structurally different health care system was generalised to a distrust of the NHS in Scotland. iii. Distrust of Western medicine approaches applied in the West was generalised to absolute terms (i.e. detrimental to health and wellbeing), to accommodate traditional culturally prescribed philosophical understandings of health and wellbeing.

## 7.2 Mind the Gaps

Analyses found support for Andersen's Model (1995), which proposes that access and use of services are associated with a range of population and individual characteristics (e.g. knowledge, beliefs, attitudes), and structural level factors, occurring at the provider and health system levels. The findings also indicate dynamic feedback loops which influenced decisions about access to health care services in Ayrshire among this study's population.



### 7.2.1 Gaps in Knowledge about Services

The overall results suggests that the BME community members who took part in this study are not benefiting from advancement in policy and service development (Chapter 1; Sections: 1.2.1.5-1.2.1.9), due to considerable gaps in knowledge about local health services, and uncertainty about how to navigate needed services, and health-related information (Chapter 4: Section: 4.1- 4.2). The finding supports previous results reporting the role of BME patient groups' lack of knowledge about services, and resources on access (Scheppers, van Dongen, Dekker, Geertzen, & Dekker, 2006). This result endorses the findings from the scoping project which found that younger BME community members believed their elders lacked knowledge about the availability of health services in Ayrshire (McKenzie, 2009). The problem of navigation and access to specialist services experienced by this particular group of BME community members has resonance with a qualitative study, which found White Scottish women residing in Ayrshire, who had, or were at risk of developing coronary heart disease (CHD) experienced problems navigating and accessing cardiology services. These same women reported feeling uncertain about "*where to go*", and "*what they should do*" if their symptoms persisted, or their condition deteriorated. There seemed to be gaps in knowledge about accessing specialist services, and gaps in knowledge about basic heart health informational support. Within the women's narratives was the perception that screening programmes are either invisible or non-existent (McKenzie, 2009). These findings indicate an interaction between population and individual characteristics, and structural factors, which act as a barrier to access for these two study participant groups. While it is important to continue to build qualitative data sets of different patient groups' experience of access, it is not possible to generalise these findings to other populations, due to the small sample size, and the methodological limitations of qualitative analyses (Chapter 8, Sections: 8.3.4).

### **7.2.2 Low Literacy and a Lack of English Proficiency (LEP)**

Analysis established communication problems were the primary obstacle preventing full and equal access to health care among participants (predisposing factor). These problems were exacerbated for some participants who had a LEP and were unable to read or write in English or in their first language (Chapter 4: Sections: 4.3). A LEP presented the greatest barrier, particularly for the Chinese and Indian participants who took part in the present study. This finding support earlier work which cites the most commonly reported barriers to access, and shared decision making experienced by BME populations is a LEP, which is compounded by structural barriers, such as not having access to either interpreter services or culturally/linguistically appropriate health education materials (Yu & Singh, 2009; Kaur et al., 2014). Reported outcomes are associated with patient dissatisfaction, poor comprehension, compliance, and ineffective or lower quality care (Baker, Hayes, & Fortier, 1996., Manson, 1988). These findings have important implications for the success of interventions to support patient engagement, which is frequently cited as a key mechanism to health system re-design, improved health outcomes, and improved patient health care experiences (Carman et al, 2013; Roseman, Osborne-Stafsnes, Amy, Boslaugh, & Slate-Miller, 2013).

Health communication problems were widely found within participants' accounts, as were varying levels of ability of participants to understand health information and to communicate symptoms and concerns. Poor health communication is associated with poorer therapeutic relationships, reduced opportunities for patients to provide and receive clinically important information, and to engage in shared decision making (Picker Institute, 2015). Low health literacy appears to be a common thread to understanding the wider health communication problems experienced by participants, and to understand the culture of silence about sexual health found within participants' accounts (Chapter 5: Sections: 5.1–5.3; Chapter 7; Sections: 7.3-7.3.2). It could be argued that feeling unable to articulate sexual ill-health, inadvertently

served to marginalise some participants in a way that suggests that they lacked power and autonomy (to talk about and seek help for their sexual health concerns). This finding is important as feeling unable to articulate sexual health needs is associated with a delayed presentation, and poorer health outcomes (Scottish Health Statistics, 2006; Siminoff, Burant, & Ibrahim, 2006). Despite poor health literacy having been previously reported in a retrospective cohort study with Chinese participants (Shi et al., 2017), there remains a paucity of qualitative literature exploring health literacy across Scotland's BME community groups.

### **7.3 Sexual Health: A Culture of Silence**

#### **7.3.1 Knowledge, Beliefs, and Attitudes about Sexual Health**

There was an expressed need within participants' accounts for basic sexual health information, particularly with regard to early signs and symptoms of commonly experienced sexual health problems; including information of what is '*normal and what is not*'. These findings have clinical significance for the men and women who took part in this study. At the time of the interview, participants reported having a general lack of knowledge about sexual disease, sexual dysfunction, and experienced difficulties concerning the use of appropriate sexual health language (predisposing factors). Despite the majority of participants being in their middle years (Appendix: 2), both men and women from all ethnic groups were unfamiliar with sexual health terminology and lacked knowledge about sexual health risks, and preventative measures to avoid infection (predisposing factors). This cluster of findings adds to the literature, which argues that very little is known about BME groups' (in the middle and older age groups), knowledge and awareness of sexual health problems across the lifespan (Cancer Research UK, 2014; Saab, Landers, & Hegarty, 2016).

The meanings ascribed to participants' silence about sexual health concerns, tend to be polarised between those expressed as having negative connotations for participants'

personal character (predisposing factor), and the importance of maintaining a sense of normalcy about their health (Chapter 5: Section: 5.1; 5.2). There was a shared belief (predisposing factor) about the positive effects derived from remaining silent about sexual health concerns, such as controlling for any sense of shame and embarrassment, whilst upholding strongly entrenched cultural values (i.e. silence as respectful) (predisposing factors). Invariably, it seems that silence was a useful communication device that enabled participants to express their preferences and to exert their power and autonomy, as a means of preserving some participants' moral values. Silence, therefore, served as a valuable device which allowed participants to manage their personal and social identities (predisposing factors). The issue of self-identity has been explored in the context of chronic ill health and disease states and has been linked with a sense of "*ownership as a symbol of the self*" (Pierce, Kostova, & Dirks, 2003). Findings from the present study may extend this concept to include the role of silence in the context of sexual health as a means of maintaining self-identity, and the boundary between the individual and society (Clarke & James, 2003; Pierce, Kostova, & Dirks, 2003). By identifying with the positive associations of silence, participants recognised that this may be indicative of their own individual characteristics (e.g. culturally prescribed norms). Consequently, it would appear that silence was understood as a useful, functional device, and an intentional rational act. These findings add to the existing literature by offering a depth of understanding of the functional nature of silence as understood by this participant group, which surpass linear and static definitions of silence. Critically, it seems that the protective function of silence was offset by more pervasive negative effects. To illustrate, the interpretation of silence about sexual health as politeness and respect had the effect of silencing participants in a way that could be recognised as a negative culture of silence, in as much as it led the majority of participants to minimise the importance of discussing their sexual health concerns (Chapter 5: Section: 5.2). It appears that a positive feedback loop, occurring between several

predisposing factors, served to maintain participants' silence about possible sexual health concerns.

### **7.3.2 A Pervasive Culture of Silence**

The pervasive culture of silence was evident in participants' experience of having never been encouraged to engage in discussions with physicians about their sexual health (Chapter 5; Sections: 5.3). The international literature on barriers to physicians discussing sexual health problems, and taking a sexual health history shows that there are significant factors that could influence patients' negative appraisal of their physician's skills. Among structural-level barriers occurring at the provider level, Wimberley, et al. (2006) found that taking a sexual health history is not considered a part of routine and preventive healthcare. Khan, Plummer, Hussain, & Minichiello, (2007), showed that a lack of time was the most commonly cited structural barrier in sexual health history taking (55%), followed by concerns that patients might feel uncomfortable if a sexual history was taken (49%) (predisposing factor). Other constraints were the presence of another person (39%) (enabling barrier), and physician's embarrassment (15%) (predisposing factor). Ho and Fernandez (2006), argued for the importance of taking a routine sexual health history, in terms of the risk associated with sexual health problems and chronic health conditions, such as chronic renal failure, hypertension, diabetes mellitus and cardiovascular disease (CVD). It is argued that a further positive feedback loop occurred between participants' predisposing factors (and possibly their physicians predisposing factors), and structural factors, which served as a barrier to effective sexual health communication.

### **7.4 Personal Perception of Risk**

A review of evidence on the use of health services by BME communities is mixed, due in part to studies often relying on uptake levels, or receipt of care as a measure of access (Szczepura, 2005); which do not allow for variations in levels of need in different populations

(Lhussier et al., 2013; Health Foundation, 2015; Ministry of Health, 2016). Need-related factors have been shown to account for the majority of the explained variability in access to primary care services, to include individual's perceived health care need, and other indicators of their health status (e.g. psychological variables, activities levels, and distress) (Andersen, 1995; Jahangir, Irazola, & Rubinstein, 2012). Findings from the present study show different patterns of a need for health care across participants' accounts, which participants' assessed by means of their personal perception of risk, occurring primarily within predisposing factors (i.e. knowledge, experiences, socio-cultural health beliefs). The Andersen model helped to identify a feedback loop between different predisposing factors (e.g. gender, ethnicity, knowledge, socio-cultural health beliefs, and health behaviours), and structural factors (e.g. community and health system levels), to help participants assess their personal perception of risk (need-related factor).

Participants' perceptions of risk-informed health decisions, and reflected complex cognitions comprising of strongly entrenched health beliefs, attitudes, and emotions experienced. The overall results extend the boundaries of the framework for stigma (Chapter 6: Section: 6.8), the concept of candidacy (Chapter 6: Section: 6.9.3; Chapter 1: Section: 1.4.1.2), and upholds traditional cognitive models of risk perception (Damasio, 1994; Slovic, Finucane, Peters, & MacGregor, 2004a, 2004b). The findings have resonance with the literature arguing that stigma is a resultant effect of "social power structures" (Link & Phelan, 2001), and is associated with broader cultural structures (Link & Phelan, 2001; Mahajan et al., 2008), which influence access to care (Hozemer et al., 2007; Deacon, 2006). The findings add to this body of work by showing that risk is inherently multidimensional and context sensitive and reflects this study's participants' individual characteristics, that have consequences for future health behaviours (Chapter 8; Section: 8.1.2.2.2), and health outcomes (Chapter 8; Sections: 8.1.2.2.3). There was strong evidence to argue that

participants' understanding of their personal perception of risk directs toward understanding risk perception within a heuristic model (Chapter 7: Sections: 7.4.1-7.4.4).

#### **7.4.1 Toward a Heuristic Model of Participants' Risk Perceptions**

Advocates argue that heuristic processing is fundamental to the functioning of the experiential system, in that it functions automatically and unconsciously (Lui, 2015). Decision and judgement research assert that heuristic processing functions to form a wide range of decisions and judgements (defined as belief and evaluations), to include risk perceptions (Slovic, Finucane, Peters, & MacGregor, 2004b). Analysis from the present study suggests that heuristics are the primary cognitive process that enabled participants to retrieve memories (about their previous experiences, knowledge, and beliefs), and to facilitate similarity and dissimilarity based matching, related to stereotypes, representations, and emotions which helped them assess their personal perception of risk.

There was evidence to show that participants used more than one type of heuristics to assess their risk (Appendix 7: Table: C). All participants seemed to used representative heuristics (Section: 7.4.2), some also made use of availability heuristics (Section: 7.4.3), while others grounded their judgements of risk within affect heuristics (Section: 7.4.4). These findings go some way to explaining the convergence and divergence of participants' risks perception.

#### **7.4.2 Representative Heuristic**

The representative heuristic can be understood as the process by which people assess risk, based on similarity with the stereotype, representation, or to other pre-existing knowledge structures (e.g. beliefs). The analysis suggests that all participants, used predisposing categories of gender, cultural norms, and lifestyle patterns (and possibly age), as a reference point to determine their personal risk. Evidence for a high representativeness heuristic was

assessed on the basis of participants' accounts denoting that they made a comparison (e.g. similarity or dissimilarity), to one or more categories outlined above. The narratives of these Chinese and Black African men offer insights to understanding the way in which they used similarity-based matching to a range of predisposing factors (i.e. ethnicity, cultural norms, and health beliefs), and to their sense of masculinity (these Chinese men only), to make sense of risk, and assess the probability of experiencing stigma. The Chinese female participants' risk perception differed from the Chinese male participants due in part to refute the same culturally defined norms that were meaningfully understood by these Chinese men, which served to protect these women from succumbing to a felt vulnerability to stigma (Chapter 6: Section: 6.4). It is argued that this evidence provides support for the use of representative heuristic and dissimilarity-based matching. In addition, participants' accounts suggest that they assessed their high susceptibility for developing Type II diabetes based on similarity-based matching (e.g. match between age, and lifestyle factors of elder brother recently diagnosed with Type II diabetes), and the low risk of developing heart disease by means of dissimilarity based matching (e.g. differences in lifestyle factors between self and other family members who were living with heart disease). Additionally, the general perception of risk of these Chinese women developing NPC and liver cancer seemed to be equal in terms of the similarity-based matching of ethnicity (predisposing), and dietary factors (e.g. high salty fish diet). Likewise, similarity-based matching of gender (predisposing) seemed to direct women in this study to assess the probability of developing breast and/or cervical cancer as equal to women of the wider population. This evidence suggests that representative heuristics requires participants to attend closely to particular characteristics of the self and others while overlooking just how common these same categories are in the wider population. In doing so, participants demonstrated a tendency to either overestimate or underestimate the likelihood of succumbing to equally threatening risks to their health and wellbeing. This evidence supports earlier work (Slovic, Finucane, Peters, & MacGregor, 2004a, 2004b), but also contributes to the risk literature by presenting evidence grounded in



participants' narratives which shows that representative heuristic was the most common heuristic used by this group, which helped participants simplify and make sense of their probability of risk, and to indicate their possible need for health care.

#### **7.4.3 Availability Heuristic**

Availability heuristic asserts that probability judgements are made by means of retrieving examples from memory (Triplet, 1992; Hayibor & Wasieleski, 2009). Evidence for participants' use of availability heuristic is embedded in the narratives of the women who took part in this study, who seemed to assess their personal perception of risk for breast cancer as being marginally higher than the risk of developing cervical cancer, due to having more knowledge and experience of cervical screening programmes than breast cancer screening interventions. This particular group of Chinese women's risk perceptions for NPC and liver cancer seemed to be heightened, due to the effect of associative learning, arising from concerns about Scottish physicians' lack of knowledge about the Chinese community's susceptibility to developing NPC and liver cancer; and concerns about their level of skill to assess and treat these diseases. These findings add to the risk and oncology literature by offering examples to show the way in which participants accessed and retrieved memories to help them make judgements about the probability of succumbing to very specific types of cancer, which took account of predisposing factors (i.e. ethnicity, knowledge, and health beliefs), and ongoing concerns about physicians' competency to diagnose and treat NPC. In addition, this evidence demonstrates the way in which participants used more than one type of heuristic to assess their risk (Section: 7.4.2 & 7.4.4; Appendix: 7; Table: C).

#### **7.4.4 Affect Heuristic**

Affect heuristic has been defined as "the specific feeling of goodness, or badness evoked by a stimulus" (Murphy & Zajonc, 1993; Damasio, 1994). Slovic and colleagues (2004b) proposed that mental images or representations are tagged to a greater or lesser degree

with affect, and it is from this “pool affect” that people make judgements. Damasio (1994) argued that affective responses are not only helpful to decision making but also comprise a “critical” element for “accuracy and efficiency”. Evidence from the current study on the use of affect heuristic comes mainly from the narratives of Chinese and Black African men. The men’s accounts reveal heavily laden negative affective statements about their vulnerability to stigma, which carried with it, a deep sense of shame. The men explicitly spoke about feeling anxious and fearful about the prospect of being stigmatised and explained the socio-cultural sensitive nature of their heightened sense of risk; despite never having actually experienced any level of stigmatising behaviour from others. This finding support previous assertions about the way in which affect heuristics induces a greater risk perception and increases the likelihood of people misjudging the actual risk to their health and wellbeing (Slovic, Finucane, Peters, & MacGregor, 2004b).

#### **7.4.5 Cognitive Errors**

In line with current research which affirms that heuristics are prone to bias (Gilovich, Griffin, & Kahneman, 2002), a number of cognitive errors were identified within participants’ accounts (Appendix: 7: Table D). It is argued that the cognitive errors led participants to find causal relationships between perceiving similar characteristics while missing other important features to assess their risk. Results show that David (Black African man), had more identifiable cognitive errors compared to other participants represented in this study, closely followed by these Chinese men. The Thai and Polish participants in the group had the least amount of identifiable cognitive errors, followed by Indian female participants. Chinese female and Indian male participants had the same number of cognitive errors but differed in terms of Indian male participants using more emotional reasoning to make sense of their personal perception of risk. These Chinese women’s cognitions were similar to that of the Black African man in terms of being more inclined to blame the medical profession for their heightened sense of risk. Collectively, men in this group had more cognitive errors (14

salient cognitive errors), compared to women (7 salient cognitive errors), who seemed to be more inclined to use emotional reasoning strategies, and to overestimate their personal perception of risk, while ignoring equally valid risks. One common cognitive error found in all participants' accounts, was 'fortune telling', which suggests that there was a shared understanding among participants that their risk perceptions were accepted without question, and as established facts. There were no instances found in the data to suggest that participants actively challenged the validity of their own risk perceptions, or perceived themselves to be susceptible to more frequently occurring health problems.

These findings support previous work investigating extensional and intuitive reasoning, and fallacy in probability judgements (Tversky & Kahneman, 1983; Gerend, Aiken, West, & Erchull, 2004). This allows for a deeper level of understanding of the ways in which participants overestimated their risk, while simultaneously underestimating their risk of experiencing other equally valid threats to their health and wellbeing. The findings add to the growing body of risk perception literature, by presenting evidence for a heuristic model, developed from analysis of the narratives of men and women from culturally diverse communities groups. Previous research has documented the tendency of heuristics to be prone to cognitive errors, but fall short of reporting what the specific errors are, or to explain the ways in which errors in thinking are influenced by predisposing factors (e.g. prior experience, knowledge, beliefs, gender, and ethnicity). The present study bridged this gap in the literature by identifying specific similarities, and differences between participants' cognitions, and showed how these influenced causal relationships, which directly influenced risk perceptions.

## 7.5 Summary

It is argued here that the primary objective of this study (Chapter 1: Section: 1.7.1), has been successfully achieved. The theoretical, ontological, and epistemological orientation employed

in the present study (Chapter 2: Sections: 2.2-2.2.4), created the opportunity to hear and understand participants' accounts, which allowed for concepts and themes to emerge from personal accounts; rather than imposing a predetermined theory, thus opening up possibilities that had not been previously considered (Smith & Eatough, 2006; Smith & Osborn, 2008), which led to unanticipated findings to emerge from the data (Chapters 3-6).

Through using IPA, it was possible to explore in-depth, how a sample of individuals from various BME community groups experience and ascribed meaning to access to health care across the three districts of Ayrshire, and in their countries of origin. Integral to IPA, and CBT/FA is a person-centred approach, which is congruent with health psychology values, concerned with the uniqueness of an individual's experiences and meanings ascribed to those experiences, and understanding the individual as a whole in the context of his/her environment (Wilding & Whiteford, 2005). The inductive approach underpinning the present study focuses on the 'life world' of an individual and regards experience as the fundamental source of knowledge (Dowling, 2007). The findings support this assertion, by demonstrating the central role of experience to participants' understandings in decision making (about access), and judgments about their health. Additionally, by means of reflection, participants were able to identify gaps in their knowledge about the health care system and to be aware of their unmet health care needs. The Andersen model helped to organise the literature review (Chapter 1), and to demonstrate the direction of effect of various population and individual level characteristics, structural factors, and how these influenced health behaviours (Chapter 8: Section: 8.1.2.2.2), and potential health outcomes (Chapter 8: Section: 8.1.2.2.3).

## Chapter 8

### 8.1 Conclusion and Evaluation

This chapter is concerned with linking the process of access found in participants' idiographic accounts, to theory, and to the literature. The results uphold Andersen's model by identifying population and individual level characteristics, and structural factors (occurring at the physician and health system level), acting in a feedback loop, which strongly influenced participants' willingness to access health care services in Ayrshire. The following sections present a series of conclusions drawn about the contribution of IPA to the main findings (Section: 8.1.1), the role of CBT/FA (Section: 8.1.2.1), and the Andersen model (Sections: 8.1.2.1- 8.1.2.2.3), in triangulating the findings. A general conclusion is presented (8.2), followed by a critical evaluation of the present study (Sections: 8.3 – 8.3.4), which directs to a series of recommendations (Sections: 8.4 – 8.4.4).

#### 8.1.1 Main Findings

This study focused on the perspectives of a sample of BME community groups' experiences of accessing general and sexual health care services in Ayrshire (Chapter 1: Section: 1.7.1). The primary theoretical model underpinning the present study was IPA (Chapter 2: Section: 2.2-2.2.3). IPA informed each stage of the design, data collection, and analyses, which allowed for the main results to be presented through the use of four super-ordinate themes: 'It's a Trust Thing', 'Mind the Gaps', 'Sexual Health: a Culture of Silence' and 'Personal Perception of Risk'. The contribution to the literature is the presentation of idiographic accounts from a sample of BME community members, demonstrating how they made sense of their trust in healthcare professionals, differing healthcare systems, and medical approaches. In addition, the findings address gaps in the literature, by deepening our

understanding of how different dimensions of trust were used by participants to form judgements, and to make decisions about whether to trust (or not to trust).

No evidence was found to suggest that any of the study's participants experienced difficulty accessing primary care services, yet the majority experienced uncertainty about how to navigate the health care system. Cycles of disempowerment were found, characterised by gaps in participants' knowledge and understanding of local health services, maintained by pervasive communication difficulties (i.e. low literacy levels, LEP), a low sense of agency, and low health literacy; resulting in unmet health care needs. In addition, structural factors (occurring at the doctor-patient, and health system level), were understood to act as barriers to full and equal access to health care for participants who took part in this study. This cluster of findings supports previous work showing that a lack of knowledge about services (Scheppers, Dongen, Dekker, Geertzen, & Dekker, 2006; McKenzie, 2009), LEP, and limited health literacy are salient predictors to low uptake of services (DeCamp, et al., 2015), which can negatively impact health outcomes (Sahm et al., 2012).

A culture of silence about sexual health was found across participants' accounts, indicating the role of silence as having an important function in preserving a sense of self, and as an unspoken expression of some participants' autonomy and power. For other participants, the silence was not a matter of personal preference, but an expression of low sexual health literacy. This finding upholds previous research on low health literacy, which affects peoples' ability to meet their health care needs (Adams et al., 2013), and adds to this literature by presenting a causal pathway to unmet sexual health needs for some participants. There remains scope to identify possible barriers to effective health communication among different patient groups, including individuals from various BME community groups (Section: 8.4.1/1). There was perceptible evidence to suggest that there is a culture of silence about sexual

health within primary care services in Ayrshire. This finding indicates a need for future research to identify possible training issues, which could possibly support clinicians to better manage consultations with patients who experience difficulty discussing their sexual health concerns (Section: 8.4.1/2; 8.4.2/4).

## **8.1.2 Triangulation of Findings**

### **8.1.2.1 CBT Functional Analysis (CBT/FA)**

Given the complexity of the main findings, CBT/FA was employed to explore cognitive structures, emotive elements, and the health behaviours found within participants' accounts. The results from this arm of analysis helped to triangulate the main findings (Chapters: 3-6), and to add to the analysis through identifying heuristics as the primary cognitive process through which participants made judgements (about their health), and when making a decision about whether to access health care services or not. Through CBT/FA, it was possible to present simple heuristic models of participants' trust (Chapter 7; Section: 7.1.3), and risk perceptions (Chapter 7; Section: 7.3.1).

### **8.1.2.2 The Andersen Model**

The Andersen Model proposes that health outcomes are influenced by population and individual characteristics, health behaviours, and the context of care (e.g. health care system, and/or the provider-level). The model is not linear or static, as it includes feedback loops, which are dynamic and interrelated (Guilcher et al., 2012). The Andersen model offered a further device by which to triangulate the main findings, by detecting positive feedback loops embedded within all four superordinate themes (Chapter 3 - 6). This helped to chart the various levels of influence of participants' access to health care (Section: 8.1.2.2.1), health behaviours (Section: 8.1.2.2.2), and health outcomes (Sections: 8.1.2.2.3).

#### **8.1.2.2.1 Access to Health Care**

Millman (1993) defined equitable access as “*care that does not vary in quality because of personal characteristics, such as gender, ethnicity, geographical location and socioeconomic status*”. Findings from the present study show that access for this group of participants’ was associated with measurable quality factors, and with participants’ perceptions of care (Fiscella et al., 2000). This finding supports, in part, previous work reporting immigrant populations experiencing a range of challenges in accessing health services of the country of their residence, related to timely, appropriate and quality health care services (European Economic & Social Committee, 2004).

A growing body of literature has explored the role of candidacy to understand access, and health service utilisation in a range of clinically significant conditions, and contexts (Baxter, 1979; Williams, 1983; Emslie, Hunt, & Watt, 2001a; Emslie, Hunt, & Watt, 2001b; Dixon-Woods et al., 2005; MacKenzie, Conway, Hastings, Munro, & O’Donnell, 2013). Need-related factors have been reported to be the most frequently reported factor predicting access (Livingstone et al., 2011; Pedersen et al., 2012). Predisposing (Hammond, Matthews & Corbie-Smith, 2010; Ani et al., 2012), and relational factors (enabling factor), have also been shown to be important to access (Brown et al., 2014; Surood & Lai, 2010; Jutagir et al., 2016; Ministry of Health, 2016). Findings from the present study add to this body of work by identifying positive feedback loops between a range of participants’ individual-level characteristics (e.g. predisposing, and need-related factors), and reinforcing structural factors (occurring at the provider, and health system level), which helped explain and predict participants’ health behaviours (Section: 8.1.2.2.2), and the potential impact on their health outcomes (Section: 8.1.2.2.3).



#### 8.1.2.2.2 Health Behaviours

##### 8.1.2.2.2.1 Help-Seeking Behaviour

The literature suggests that help-seeking behaviour (HSB) is an important device for exploring and understanding the delay, and prompt action across a variety of health conditions (Galdas, Johnson, Percy, & Ratner, 2010; Cornally & McCarthy, 2011; McKenzie, 2009). The analysis identified differing patterns of HSB in this particular group of BME community members. Preventative health strategies were regarded by several participants to be enveloped within individual-level predisposing factors (e.g. socio-cultural health beliefs), which do not usually involve actively seeking out medically based preventative health screening programmes (Chapter 4; 4.2). However, female participants were more likely to take up offers of preventative screening services (e.g. Pap test) and were less likely to delay seeking help, than male participants, but only when it “is *absolutely necessary*”, or as “a *last resort*”. These findings add to the health literature by understanding the role of participants’ socio-cultural health beliefs about access (predisposing factor), and the relative role of women’s value-driven judgements (predisposing factor) have in determining the appropriateness of engaging in health help-seeking behaviour (i.e. accessing services). The finding supports previous studies reporting a trend of underutilisation of preventative health services (Cherry, Woodwell, & Rechtsteiner, 2007), and clinically appropriate health services (Hammond, Matthews, & Corbie-Smith, 2010), among BME men. The results also support the literature reporting on the propensity of men to delay accessing screening services and routine check-ups, waiting longer after symptom onset before seeking care (Hammond, Matthews, Mohottige, Agemang, & Corbie-Smith, 2010; Powell, Adams, Cole-Lewis, Agyemang, & Uptom, 2016). The lower uptake of screening service among the men who took part in the present study adds to this body of literature by, identifying the primary factors influencing the underutilization of services. The findings indicate that access to health care for this particular group of men can be yoked with medical mistrust (Chapter 3; Chapter 7: Section: 7.1.2 - 7.1.4), a LEP, low health literacy, a lack of knowledge about preventative services (predisposing factors), with problems navigating services (structural factor: health

system level) (Chapter 4; Chapter 7: Sections: 7.2 - 7.2.4), and as a consequence of traditional masculine beliefs (i.e. Chinese male participants only: predisposing factor) (Chapter 6: Section: 6.3).

#### **8.1.2.2.2.2 Compliance**

Poor compliance to medical treatment and advice has been associated with treatment failure, and poorer health outcomes (Kutzelnigg et al., 2014; AIDSinfo, 2014). Compliance to health care ensures that patients obtain timely (Fiscella et al., 2000), and appropriate health care in situations of perceived need for care (Levesque, Harris, & Russell, 2013). Overall, participants' compliance to medical advice and treatment was low. Population and individual characteristics, and reinforcing structural factors were found to exert a strong effect on compliance in this study's population. Perceptions (predisposing factor) about the quality of care previously received in primary care services served as a block to compliance for participants. Compared to other participant groups in the present study, compliance to medical advice, and treatment offered in primary care services in Ayrshire was lower among the men and women from the Chinese community (predisposing factors). Situated within their accounts were a range of predisposing (i.e. socio-cultural health beliefs; LEP, low literacy, and low health literacy levels), and structural-level factors (quality of services, and treatments offered in Hong Kong, compared to Ayrshire). A positive feedback loop was found among structural barriers to access in Ayrshire (e.g. problems with navigating health services; no access to interpreter services), predisposing (distrust in the health system); and need-related factors (e.g. risk perceptions), which accounts for the low levels of compliance, and lower uptake of services in Ayrshire among Chinese participants.

#### **8.1.2.2.2.3 Health Outcomes**

Evidence suggests that people with no RSC are at greater risk of experiencing poorer health outcomes and health disparities (Starfield, Shi, & Macinko, 2005; McKnight et al., 2017).

The literature also argues that individuals who LEP, have low health literacy (Adams et al., 2013; Rudd, Groene, & Navarro-Rubio, 2013; DeCamp et al., 2015), and experience structural barriers to accessing services (NHS Education for Scotland, 2016), are at greater risk of experiencing poorer health outcomes (Decamp, et al., 2015). Collectively these findings make it possible to argue that the poor uptake of health care in Ayrshire among the study's population, places this group of BME community members at greater risk of experiencing poorer health outcomes. Among participants, it is the men and women from the Chinese and Indian communities who fit the profile outlined above, more than other participant groups. That said, participants from the Chinese community who can afford to do so (enabling factor), return to Hong Kong on an annual basis to undergo a comprehensive health screening programme, and receive a synergy of Western and Chinese medical treatments, from a health system they respect and trust (predisposing factors). It is argued here that predisposing (ethnicity, socio-cultural health beliefs, knowledge, and participants' prior experience), and enabling factors (e.g. higher income), have a positive impact on the patterns of help-seeking behaviour, and health outcomes of this particular sample of Chinese community members. This finding cannot be generalised to other individuals' with lower incomes, who may not have the same opportunities open to them. David (Black African) is also considered to be at higher risk, due to having no RSC, and having no intention to access health services in Scotland or to return to his homeland for health care now, or in the future. The Thai and Polish participants (predisposing factors: female gender, and ethnicity), were found to be at lower risk of experiencing poorer health than any of the other participant population, due to a range of predisposing factors (e.g. health beliefs, knowledge, higher levels of agency, and self-efficacy), and having fewer cognitive errors compared to other participants (Appendix 7: Table D). These women also had strong social support networks, and a level of income (enabling factors), which allowed them to return to their respective homelands to access health services in which they trust (predisposing factor). Social support and higher incomes are associated with better adaptation to ill health, lower risk health

behaviours, improved health status, lower risk of experiencing ethnic health inequalities (Syme & Berkman, 1976; Schoenbaum, Schoem, Nicholson, & Cantor, 2011; Jutagir et al., 2016); and can enable access to health services and resources (Dixon-Woods et al., 2005). For the study's participants, particularly those who have fewer social support networks, and lower incomes (which may prohibit them from returning to their homeland to access health services), it is argued that community-based patient engagement strategies (Sections: 8.4.3/4/5), may extend the opportunity to obtain timely and appropriate health care in situations of perceived need for care (Levesque, Harris, & Russell, 2013). This creates the potential to improve access across various levels of the health system for this group of BME community members; thereby possibly improving health outcomes (Carman et al, 2013; Danis & Solomon, 2013).

## 8.2 Conclusion

In conclusion, the finding clarify the role of population and individual-level factors (e.g. Predisposing Factors: socio-cultural health beliefs, knowledge, and experience, ethnicity, gender, and possibly age; Enabling Factor: income and social support; Need-Related Factor: risk perceptions), and structural factors (occurring at the health system and provider level), on participants' trust, risk perceptions, intentions to access services (health behaviour), and possible health outcomes. It is argued here that analysis delivered an in-depth "*analytic commentary*", which led to useful insights that have wider implications for research (Chapter 8: Section: 8.4.1), clinical practice (Chapter 8: Section: 8.4.2), service development (Chapter 8: Section: 8.4.3), and health promotion Chapter 8: Section: 8.4.4), in Ayrshire (Chapter 8: Section: 8.4).

It is also argued that the primary objective of the present study was achieved (Chapter 1: Section: 1.7.1). In addition, unanticipated findings and insights were found through the presentation of four superordinate themes (Chapters: 3–6). By means of CBT/FA, it was

possible to present a heuristic model of participants' trust (Chapter 7: Section: 7.1.4), and their personal perceptions of risk (Chapter 7: 7.3.1 - 7.3.5), which were meaningfully understood by the men and women who took part in this study. The analysis identified a range of population and individual characteristics (e.g. socio-cultural beliefs, perceptions, attitudes, knowledge, and health literacy), health behaviours, and structural factors which influenced participants' ability to discuss their health concerns. Collectively these factors served as barriers to access, which have the potential to adversely affect health outcomes of some of the study's participants. Additionally, this study addressed the gap in the gender literature by including both men and women from a range of ethnically diverse community groups. Analysis of participants' accounts addressed concerns in the literature, which regard men as a homogeneous group, to arguing for differences and diversity among men (Shoskes et al., 2016; Hesse-Biber, & An, 2015). By identifying participants' experience of risk perception, it was possible to argue for the role of the hegemonic masculinity on the Chinese male participants' perceptions of risk. This study has implications for the future direction of research, which aims to be gender-sensitive (White & Lockyer, 2001). Gender-sensitive research argues for the importance of including both men and women in research, so as to promote and enhance the health and wellbeing of both men and women (Doyal, Payne, & Cameron, 2003). In addition, this study has bridged the gap in the culture literature by integrating a culturally-sensitive approach to the design and aligning this to the recruitment, analysis, and presentation of the perspectives of several culturally rich and diverse BME community groups. In addition, this study has bridged the gap in the culture literature by integrating a culturally-sensitive approach to the design and aligning this to the recruitment, analysis, and presentation of the perspectives of several culturally rich and diverse BME community groups. Lastly, the present study addressed the need to shift the research focus from clinical factors to a more complex and integrated map, by charting the key factors, processes, structures, and outcomes related to the experiences of the study's participants' pathways to health care.

## 8.3 Evaluation of the Present Study

### 8.3.1 Critical Perspective

Critics may argue against the use of IPA to investigate neurocognitive processes which underpin participants' judgements about their personal perception of risk. It is argued that the representative, availability, and affective nature of risk perception found in the data is of particular relevance to IPA, given the ontological and epistemological stance of this research method (Smith, 2011a). The ideographic nature of IPA analysis (Smith et al., 2009), allows for a deep and thorough exploration of participants' accounts, addressing "*the wholeness and uniqueness of the individual*". The wider aim of IPA is to offer a comprehensive and exhaustive portrayal of how participants make sense of their world (Malim, Birch, & Wadeley, 1992, pp. ), and to understand more fully the ways in which people form judgements and make decisions (Peters, McCaul, Stefanek, & Nelson, 2006). Critics may also contest the modelling of participants' trust and risk perception. It is argued that the heuristic models are firmly embedded within participants' accounts. Rather than breaching the boundaries of IPA, it is proposed that this modelling has achieved the wider aims of IPA (identifying the individuals' cognitive, linguistic, affective, and physical experiences) (Finlay & Ballinger, 2006, pp. 136-159). Although it is not the explicit remit of IPA to develop theory, authors argue that IPA studies can contribute to, and influence theory (Pringle Drummond, McLafferty, & Hendry, 2011). In addition, conceptualising participants' perspectives opens up a dialogue about the contribution IPA can make to the wider health literature, and challenge traditionalist notions about the theoretical transferability of IPA (Smith et al., 2009). It is argued, that tensions around IPA studies being too "*subjective, intuitive and impressionistic*" (Malim, Birch, & Wadeley, 1992), were challenged in this thesis, by going beyond merely describing participants' experiences (Brocki & Wearden, 2006), and by not being constrained by traditional methods used in IPA analysis. By extending the boundaries of traditional approaches to IPA, it became possible to add a sense of depth, and breadth, and purpose to the analysis, while also identifying which variables were important

(Smith et al., 2009); a dimension that traditional thematic analysis often lacks. In doing so, this study not only “*uncovered meanings*” (Sundin, Bruce, & Barremo, 2010), but also “*interpreted the meanings*” (Van der Zalm & Bergum, 2000), and found commonalities, while explaining difference within, and across participants accounts.

### 8.3.2 Core Principles

Yardley’s (2000) core principles for evaluating the validity of qualitative research was used to guide and direct all stages of the present study (Chapter 2). Integral to the design of this study was a clearly defined research objective, which resonates with the findings from an earlier scoping study, and the available literature on BME health (Chapter 1), thereby establishing the appropriateness of the present study. Every effort was made to ensure that sufficient detail was provided about the design and methods used (e.g. sampling techniques, interview skills, data collection, analysis, results, and conclusions were drawn), to help the reader assess the quality of this study, and to determine the rigour, transparency, and the commitment of the investigator to the research process.

Coherence was achieved by establishing multiple and independent techniques and coding systems to confirm analysis, and by using cross-references, and charting the processes from the interview to analysis and conclusion; which reinforced the link between the data, the literature, theory, and conclusions (Strauss & Corbin, 1990, 1998). All cases were included and reported, which counters critics of qualitative research who assert that studies such as this one rely on cases that are aligned to research objectives, and support conclusions (Silverman, 1993). Coherence was also achieved by conducting two negative case analysis (Chapter 3: Sections: 3.6 & Chapter 6: Section: 6.8), which opened up the possibility to explain more fully emergent patterns, to test for internal validity, and helped to explain more fully the ways in which participants understood and made sense of their experiences.



It was a matter of utmost importance for the researcher to be aware of her influence on the analysis, as a focus on objectivity was a personal goal. Through a tireless process of working reflectively, and reflexively it became possible to identify the ways in which aspects of the researcher's experience, epistemological and ontological stance (Chapter 2: Section: 2.2.4), shaped the findings over time. Through critical reflection, it was possible to use reflexivity as a device to monitor the extent to which she was able to engage with the data over time, and documenting how this influenced different stages of analysis. Working in this way facilitated adherence to Yardley's (2000) guiding principles of transparency, of being aware of maintaining sensitivity to context, while also being actively engaged in auditing the research process. The impact and importance of the findings were discussed in line with the extent to which analysis offered support to the existing literature, the contribution it made to theory, and the wider health literature. The implications for future research, clinical practice, service development, and health promotion were aligned with analysis, and conclusions were drawn.

### **8.3.3 Strengths of the Present Study**

While there remain issues with the concept of saturation, and debate about data never being truly saturated, due to the possibility of new perspectives being uncovered using different theoretical frameworks, and analytic tools (Tracy, 2010). It is argued here that the present study achieved sampling saturation as the sample of BME community members (Chapter 2: Section: 2.5; Appendix: 2; Table: A), were both appropriate, and adequate (Bowen, 2008; O'Reilly & Parker, 2013), to address the objective of the current IPA study, while acknowledging that the participants may not be representative of the wider BME population in Scotland. Data collection saturation was achieved by setting aside ample time preparing for, and implementation individual interviews (Chapter 2: Section: 2.6.1; Appendix: 4), including seeking additional training in clinical interviewing skills (Chapter 2: Section: 2.7.1) (Tracy, 2010). Data saturation was also evidenced by the presentation of rich and full data (Chapters 3 – 6), which not only addressed the main objective of the study (Chapter 1:



Section: 1.7.1), but uncovered unanticipated findings, which support, and add to the existing literature. In addition, by means of IPA analysis, and the triangulation of results, using CBT/FA, and the Andersen' model, "*no new themes, findings, concepts or problems were evident in the data*" (Francis et al., 2010). Theoretical saturation is understood as "no new insights emerging from the data (Bryman, 2001). It is argued that theoretical saturation was achieved by means of implementing a range of analytic tools, and skills; and linking participants' accounts to theory, and to the existing literature, which allowed for the development of a heuristic model of participants' trust (Chapter 7: 7.1.3-7.1.4), and their personal perceptions of risk (Chapter 7: Sections: 7.4.1 – 7.4.4). In qualitative research, theoretical saturation is usually only achievable in the grounded theory approach (Francis et al., 2010). It is argued here that the analytic tools and skills used, add to the IPA literature which challenges researchers to reflect on emergent constructs in IPA analysis, and the relationship between IPA and other phenomenological approaches (Smith, 2004). It is also argued that the methods used in the present study meet the challenge set by Smith (2004), in which he posits that IPA research might develop, to include, micro-textual analysis, single case studies, and recruiting different groups of participants.

While it is acknowledged that the sample of BME community groups who took part in this study may not necessarily be representative of the wider BME population residing in Scotland, this is not considered a limitation in IPA studies; but rather, it is a choice (Chapter 2: Section: 2.5) (Smith, 2011a). Recruiting men and women from various BME community groups were useful in terms of examining how people from diverse groups construct meanings about their experiences of accessing health care, which can be used in cultural or indigenous psychology, which focuses on the emic perspectives of participants (Pietkiewicz & Smith, 2014).

A range of philosophical and epistemological perspectives was used in this study. In practical terms, these translate into a synergy of methods and strategies implemented at various stages of the research process. This study demonstrated the practical value of applying an ethnographic approach (a key aspect of IPA), which involves understanding the social world or culture, the shared behaviours, beliefs and values of particular groups. Phenomenology was used to help describe how participants construct and make sense of their social world, and the meanings they attach to their experiences of access to health care. Applying interpretivism helped to accentuate the importance of understanding participants' perspectives in the context of their social-cultural environments and the individual circumstances of their lives. This has implications both for the balance between inductive and deductive approaches to the research process and for the ways in which analyses and interpretations of the data were achieved. In addition, the integration of hermeneutics promoted personal responsibility of the researcher, to become a reflexive practitioner, and to be better equipped to understand how participants made sense of themselves, and the topic under investigation. This study captured a moment in time whereby participants reflected on their health care experiences, understood themselves, and made sense of their own personal characteristics, beliefs, emotions, and health behaviours, in the context of accessing two distinct health care systems. In addition, this study was also able to document participants' experiencing insight into their personal perception of risk, and their unmet health care needs.

Smith, Larking, and Flowers (2009) argues that if the interpretative function of IPA is "rich", and "transparent", and appropriately relates to the current literature, readers should be able to evaluate the quality of the study. At the heart of the present study is its strong methodological design (Chapter 2), integral to which were a range of skills which enabled the researcher to work flexibility and transparently (Smith et al., 2009). Working in this way made it possible to address concerns in the literature about addressing cultural sensitive

approaches, and gaps in the 'gender neutral' research. This was achieved by not following the traditional convention of having a narrow and homogeneous sample. In doing so, it became possible to explore convergence and divergence within and between participants' accounts (Smith et al., 2009), and to firmly establish links between participants' accounts, theory, and the literature. It is argued that this thesis has met the criteria by which the effectiveness of IPA studies can be judged, in terms of "*shedding light on a broader context*" (Smith, Larking, & Flowers, 2009, pp. 51).

By investigating negative cases, it was possible to gain valuable insights from the data, which previously were not evident in the early analysis. This level of analysis added depth and density to the findings, as it discovered subtle characteristics of the sample, and captured the full complexity of the data on which it is based. This level of analysis not only allowed for a triangulation of the sample, methods, and theory, but established the validity of the early analysis, and helped to achieve analytic and theoretical saturation (Chapters: 3 - 7). CBT functional analysis (CBT/FA) was used to explore negative cases. It is argued that CBT/FA is compatible with IPA in that it is an idiographic assessment, concerned with understanding individuals' characteristics, and can help to identify specific cognitions, emotions, and behaviours, and any subsequent interactions. CBT/FA can be a useful device to help overcome the categorical limitations of IPA classification by accommodating a more dimensional, and process level of analysis. This analytic tool was useful when conducting the negative case analysis, particularly in terms of charting the cognitive processes involved in decision-making and forming judgements (Chapter: 7; Sections: 7.1.6; 7.4 – 7.4.4). In using the Andersen model as an overarching framework in the final stages of this study, it was possible to examine the association of population and individual characteristics, structural factors, health behaviours and health outcomes. It was also possible to argue that the Andersen Model is compatible with IPA and CBT/FA, as this framework is concerned with the individual, context, and to understand and predict pathways to health care as being

influenced by dynamic and interactive forces which influence help-seeking behaviour, and health outcomes. Finally, it is argued that this study was at low risk of attrition bias, due to having complete outcome data: 1. the inclusion of all cases, 2. none of the participants left the study; and 3. there have been no requests from participants for their accounts to be removed at any stage of the research process. It is further argued that the risk of bias in this study was limited, when taking account of the researcher's epistemological and ontological perspective (Chapter 2: Section: 2.2.4), the primary objective of the study, the range of methods used to analyze and triangulate the main results, limitations acknowledge (Chapter 8: Section: 8.3.4), and conclusions drawn.

#### **8.3.4 Limitations of the Present Study**

Given the nature and complexity of access to healthcare and BME health, it is possible that some important studies have been missed in the literature review. Attempts were made to minimise this as much as possible by searching numerous databases, accessing the grey and unpublished literature, and hand searching key articles.

Despite the role of key community members recruiting participants at community engagement events throughout Ayrshire, it is acknowledged that the snowballing sampling process (Chapter 2: Section: 2.4), is subject to selection bias. It is argued that this study was at high risk of selection bias, through possibly recruiting a "convenience sample" of participants; which is limited in terms of recruiting a non-representative sample. In an attempt to reduce the risk of selection bias, participants were selected using pre-defined criteria (Chapter 2: Section: 2.3 - 2.3.1). Additionally, the study aimed to be inclusive in terms of recruiting a sample of participants from a wide range of BME communities residing in Ayrshire. The Muslim community (residing in East Ayrshire), were the only BME group rejecting offers to take part in this study. The spokesperson representing this community expressed concerns about anonymity, due to "*the current political climate*". No other data

was available to ascertain the extent to which the spokesperson was expressing his own personal views, and preferences (not to take part), or if these were shared concerns within the Muslim community. It is acknowledged that this study was vulnerable to a high risk of performance bias, due to the presence of the interpreter(s), and other community members during the interview with participants from the Chinese community; which may have inhibited participants from expressing their concerns more fully, particularly in the context of sexual health. This situation was managed by recording the interviews, taking additional field notes, and by extending the invitation to participants to speak privately, or at a later time (face to face; or over the telephone). The study was also at a high risk of detection bias due to not randomly assigning or concealing participants. It is acknowledged that masking was not possible due to the nature of this thesis, which asked the researcher to work autonomously (on all the key tasks of the study: including, the design, recruitment, data collection, and management, analysis, and report writing).

Due to the small sample size, the non-homogeneous group of participants, and the theoretical orientation of the present study, it is not possible to make generalisations from the sample of participants to the wider population. It is acknowledged that in some cases, it was not possible to generalise beyond individual participants (e.g. David, Black African). Smith and Osborn (2008) advocate small sample sizes in IPA studies, including individual case studies. However, sample groups should be as homogeneous as possible to allow the researcher to explore the phenomenon as it is shared by a specific group. As the present study's population was not homogeneous in terms of predisposing factors (e.g. age, gender, and ethnicity), the complexity of analysis was increased, and the allocated time to complete the study was extended to attend to idiographic (in-depth analysis of single cases, in their unique context), and phenomenological concerns (e.g. explore the ways things appear to individual participants), and to ascertain the extent to which there were shared experiences, differences and similarities in access within this diverse group of participants.

Overall the Andersen model was helpful as a structured and standardised tool to compare and contrast the reviewed literature, theory, participants' experiences, and in discussing the results. However, the full benefits of the model were not fully realised as it was not used as the primary model for data collection, and analysis of the data. The model is comparatively flexible. However, this proved challenging when categorising certain variables within domains, as variables may arguably fit into numerous categories (Guilcher et al., 2012), which required careful consideration in deciding how to specify the relative importance of different factors.

## **8.4 Recommendations**

The following recommendations can inform research, clinical practice, service development, and health promotion by initially disseminating the results from the present study; and searching for opportunities in Ayrshire to form sustainable relationships with clinicians, and service providers interested in the BME health, and working to improve access to health care, and health resources for BME community groups.

### **8.4.1 Research**

1. Future research should aim to sample larger sections of the BME population in Scotland, using multi-design methods and multidisciplinary groups to identify barriers to effective health communication, including communication regarding general and sexual health needs.
2. Future research should also seek the perspectives of health care professionals to inform the wider health development of any issues, training needs, and possible communication problems experienced when working with BME patient groups (including sexual health concerns).
3. Identifying the needs of BME patient groups, and healthcare professionals will allow the wider health development to work towards developing a more culturally sensitive and

A qualitative study exploring the experiences of access and pathways to health care among BME community groups residing in Ayrshire responsive health care service in Ayrshire.

#### **8.4.2 Clinical Practice: CPD: Primary Health Care**

1. Health psychologists are well placed to develop continued professional development (CPD) initiatives for clinicians and managers of primary care services to:
2. Reflect on the conditional nature of trust, and to explore ways in which to build sustainable trusting relations with their local BME community groups.
3. Improve health communication at the level of the patient-physician interaction, which may help to reduce barriers to care for some individuals from Ayrshire's BME communities.
4. Offer training to support clinicians to be more able to enquire about and to elicit sexual health information from BME patient groups, while building the capacity of clinicians to break the silence about sexual health.
5. A Strength-Based CBT approach is recommended as the most appropriate level of intervention for clinicians working with these Chinese men, as it does not seek to change individuals' beliefs per se, but to help to identify strengths people already possess to promote positive health behaviour, and building the capacity (using a model of positive coping/resilience from these existing strengths) of individuals.

#### **8.4.3 Service Development**

1. Develop culturally sensitive, person-centred care packages, which aim to move away from the paternalistic medical model, to improve understanding of the role of predisposing factors (e.g. culture, gender; including different masculinities), cognitions, and emotions, on health decision making, and health behaviours, to facilitate: a. shared decision making; b. develop BME patient groups trust in primary care services, and by association, the wider health development; c. challenge risk perceptions

2. Develop linguistic competence in primary health care services, which aim to support clinicians' efforts to communicate effectively with BME patient groups, and convey health information that can be readily understood by ethnically diverse audiences (Anderson, 2003).
3. Develop professional interpreting and translating services for BME patients groups within primary care services who LEP, so as to reduce barriers to fair and equal access to health care.
4. Develop advocates to health, to improve health literacy, and reduce the low sense of agency found in participants' accounts to:
5. Empower, and build the capacity (e.g. address low literacy levels) of BME community groups, as a means of improving health communication.

#### **8.4.4 Health Promotion**

Develop gender appropriate resources that are culturally and linguistically sensitive, aimed at:

1. Outlining fixed and modifiable risk factors for heart disease, and type II diabetes, and breast cancer.
2. Demonstrate self-examination techniques for the early detection of breast cancer.
3. Inform older aged BME participants about changes to sexual health across the lifespan.



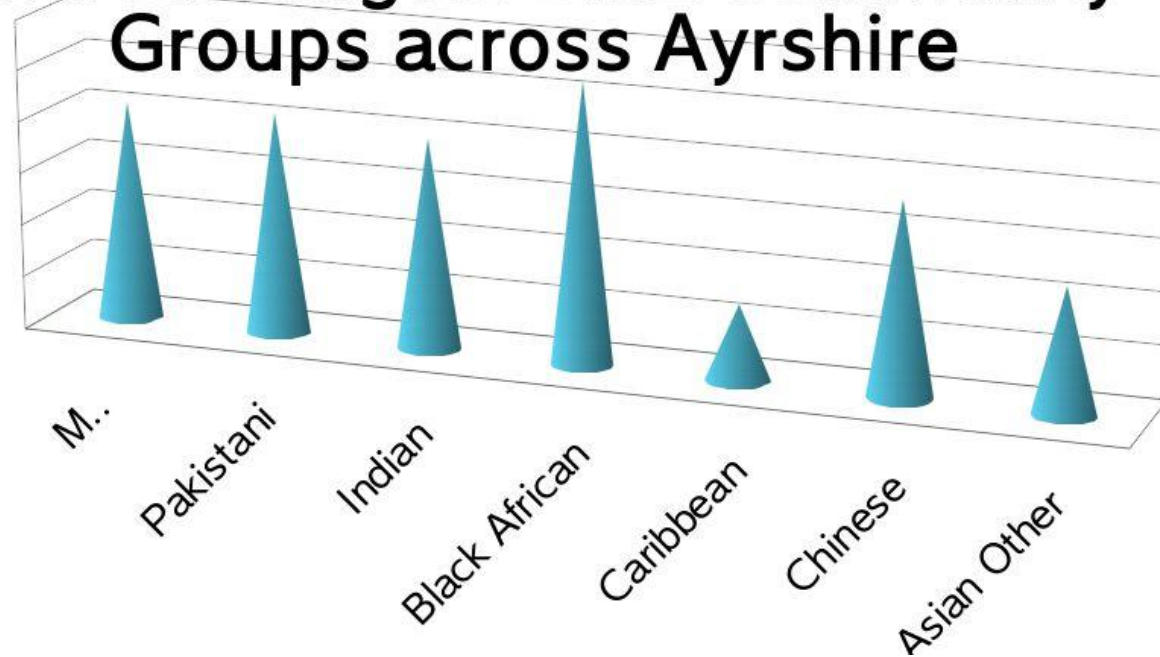
## Appendix Sections

<b>Appendix 1</b>	Chart A. Largest BME Groups Across Ayrshire
<b>Appendix 2</b>	Characteristics of Participants
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# Appendix 1

## Chart A. Largest BME Community Groups across Ayrshire

## Chart 1: Largest BME Community Groups across Ayrshire



**M = Mixed Race**

Source: Amended data from Census (2011)

## Appendix: 2

**Table A: Participants' Characteristics**

<b>Ethnicity</b>	<b>Gender</b>	<b>Age</b>	<b>First Language</b>	<b>Employment Status</b>	<b>Time Spent in Scotland</b>
<b>Indian Sikh</b>	Male	52	Punjabi	Restaurateur	27 years
	Male	65	Punjabi	Retired (aeronautical engineer)	34 years
The Punjab					
	Female	54	Punjabi	Shop Owner	35 years
	Female	45	Punjabi	Shop Owner	30 years
<b>Chinese</b>	Male	59	Traditional Chinese	Restaurateur	22 years
	Male	54	Traditional Chinese	Restaurateur	20 years
Hong Kong					
	Female	58	Traditional Chinese	Restaurateur	28 years
	Female	60	Traditional Chinese	Restaurateur	35 years
Thai	Female	42	Thai	Nurse	15 years
<b>Black African</b>	Male	32	Ngonoi	Construction worker	3 years
Zambia					
<b>Polish</b>	Female	27	Polish	Waitress	3 years
Poland					

## Appendix: 3

### Semi-Structured Interview Schedule

#### 1. Explore participant's experiences of health care system

Could you tell me about your experience of using the health care system?

**Prompts:** Visiting your GP, hospital appointment(s), visiting your dentist, screening services and/or sexual health services.

#### 2. Explore participant's knowledge and awareness about the range of health care services

Can you tell me what services are available in your area?

**Prompts:** Screening services for diabetes, heart disease, sexual health, mental health services, etc.

#### 3. Explore potential barriers to accessing health care services or medical care.

Have you experienced any problems whilst seeking help for a medical problem?

**Prompts:** Communication problems, waiting times, travel, financial constraints, etc.

#### 4. Explore potential barriers to undertaking preventative health practices

Have you undertaken any preventative health practices to prevent getting ill? If so, could you tell me about your experience?

**Prompts:** e.g. uptake and attend screening programmes (e.g. Pap tests, blood glucose tests, blood pressure and cholesterol checks)?

#### 5. Do you have any recommendations that you think would improve the services you use or services you would like to use?

**Prompts:** Informational support, translators, better access, different types of services to meet needs; etc.

## Appendix 4

### Participants' Information Sheet

#### Information

You are invited to participate in a research study that is interested in your community's experiences of using health care services in Ayrshire. The study is being conducted by Elizabeth McKenzie, who is a health psychologist in training, studying at Queen Margaret University in Edinburgh.

#### What is the study about?

If you decide to take part in the study, you will be asked general questions about your views and your experience of the health services in your area, and also any difficulties you may have experienced in accessing services, and any suggestions you may have to improve your experience.

#### Why have I been invited to participate in this study? Do I have to take part?

Your participation is voluntary, and you can leave the study at any time without explanation. Your participation in this study may not be of direct benefit to you but could help future patients of the NHS. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form.

#### What does this study involve?

If you decide to take part, Elizabeth will meet you and discuss the project in more detail, answering any questions you may have. You will then be invited for an interview; this can be in your home, or at a community building. The interview will take about 1-2 hours. The interview will be tape-recorded, and you will be asked to give your written consent.

#### Confidentiality and Anonymity

All confidential information, including your name, your address personal, telephone number, and your statements will be anonymised. This will make sure that your identity is protected.

This research has been authorised by the Ethics Committee at Queen Margaret University, Edinburgh. If you have any questions about the study please contact Elizabeth or Professor McVittie. Dr Vivienne Chisholm can be contacted if you would like to have independent advice about the study. Thank you for taking the time to read this information sheet. We would be very grateful if you feel able to take part in this research project.

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## Appendix 5

### Consent Form

Title of Project: A qualitative investigation exploring possible barriers to healthcare and unmet health needs of the Black and Minority Ethnic groups in a rural Scottish community

By signing this form you give your consent to your participating in the project whose title is at the top of this page: and consent to the information you provide is used for publication and to inform the wider health development of key findings.

You should have been given a complete explanation of the study to your satisfaction and have been given the opportunity to ask questions. You should have been given a copy of an information sheet to read and to keep. Even though you have agreed to take part in this study, you may withdraw your consent at any time without the need to explain why.

**Consent:** \_\_\_\_\_ (Print)

I give my consent to the research procedures above, the nature, purpose of which have been described to me by \_\_\_\_\_

Participants Signature \_\_\_\_\_

Date \_\_\_\_\_

Researchers Signature \_\_\_\_\_

Date \_\_\_\_\_

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## Appendix: 6 Table B. Superordinate themes & BME Groups

BME Group	It's a Trust Thing	Mind the Gaps	Sexual Health: a culture of silence	Personal Perception of Risk
Chinese	X	X	X	X
Thai		X	X	X
Black African	X	X	X	X
Polish	X	X	X	
Indian Sikh	X	X	X	X



## Appendix: 7

**Table C: Heuristic Model: Personal Perception of Risk**

**Table D: Meaning of Cognitive Errors**

Appendix: 7 Table C: Heuristic Model: Personal Perception of Risk

Participants	Emotional Reasoning	Blaming	Control Fallacies	Personalisation	Catastrophising	Fortune Telling
Chinese men (x2)	✘		✘	✘	✘	✘
Chinese Women (x2)		✘			✘	✘
Polish Woman						✘
Thai Woman						✘
Indian Men (x2)	✘				✘	✘
Indian Women (x2)					✘	✘
Black African Man	✘	✘	✘	✘	✘	✘

## **Appendix: 7 Table D: Meaning of Cognitive Errors**

Emotional Reasoning	Judgements about personal perception of risk were guided by emotional reasoning rather than more rational thinking
Blaming	Blaming the medical profession as heightening personal perception of risk
Control Fallacies	Feeling externally controlled, which made participants feel helpless, fatalistic, and disempowered
Personalisation	Holding self overly responsible. Comparing self to others
Catastrophising	Magnifying or exaggerating personal perception of risk, while ignoring equally valid risks to health
Fortune Telling	Accepting that risk perception(s) are an established fact, without challenging them.

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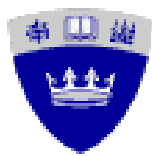
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A qualitative study exploring the experiences of access and pathways to health care among BME community groups residing in Ayrshire



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